PenCLAHRC Question Prioritisation 2015

Priority briefings index

As before, when considering the question, we ask you to think about the PenCLAHRC criteria for research prioritisation:

- The size of the health problem
- The potential for health improvement from answering the research question
- The practicality of answering the research question
- Whether the South West is a good place to do this research
- Alignment with local healthcare priorities.

PRIORITY BRIEFING ID 1

The purpose of this briefing paper is to aid Stakeholders in prioritising topics to be taken further by PenCLAHRC as the basis for a specific evaluation or implementation research project. This paper was compiled in 2-3 days. The briefing is in four parts:

- General context
- The question in a structured format
- What the research evidence says
- Alignment with PenCLAHRC research priority criteria

QUESTION: Can a day care intervention help to establish social links and support between new parents and retired people leading to improved wellbeing for parents and older people, with no harms to children?

General context and definitions: This question stems from observations of loneliness among the retired population and new parents, both populations may not have local family support or opportunities to socialise. Loneliness has been defined as an individual's subjective feeling of lacking desired social contact[1]. Although evidence suggests that loneliness is most common in the elderly; new parents, particularly single parents, may also be affected by loneliness. Reduced social contact, being alone, isolation and feelings of loneliness are associated with reduced quality of life[2].

Intergenerational interventions involve interaction between members of younger and older age groups for the benefit of all participants[3]. Intergenerational interventions have been in existence for several decades to address a range of social issues. Most of these programs involve older people and young children to support educational success, understanding, and reduce ageism[4-6]. Such programs have addressed various social issues such as the involvement of the elderly in providing child care, and supporting school dropouts, drug addicts, etc., in order to promote intergenerational exchange between the young and the elderly within local communities[7].

Most research on intergenerational day care involves combined care for both older people and children (e.g.[8]). Research relating to intergenerational social support where older people are supporting childcare typically relates to support within the family (e.g.[9]). There is a lack of research on intergenerational care that involves both new parents and older people outside of the family or interventions that address loneliness in new parents more generally.

The question in a structured format: In considering this as a research question, we could frame it as following:

Population:	Retired population and new parents
Intervention:	Social support intervention, in a range of potential settings, which may or may not involve health and social care professional/s
Comparator:	Intervention as above, but includes either only retirees or only new parents
Outcomes of Interest:	Participant satisfaction, contact outside of the group setting, measures of social isolation and loneliness

What the research evidence says: There have been no systematic reviews or controlled trials investigating interventions used to improve social support between new parents and older people. Parenting support provided by older people is popular in Japan, where a 2010 cross-sectional study examined the influence of child-care support by elderly persons on mothers' child care-relate stress[10]. The purpose of the intervention was to provide a place where mothers who found it difficult to join groups could make friends easily, connect with other mothers and persons in the community, and have consultations about parenting, all facilitated by older people. The study did not find overall that participation in the intervention improved social isolation compared to the control group. However, mothers in the intervention group with greater intervention participation had significantly higher social isolation scores than those with low participation.

Much of the research into interventions to reduce loneliness has focused on older people. In 2011 researchers at the University of Exeter Medical School conducted a systematic review assessing the effectiveness of interventions designed to alleviate social isolation and loneliness in older people[11]. Although none of the studies reviewed included interventions that involved new parents, two studies are relevant to this research question. Rook and Sorkin investigated a foster grandparent programme, finding no effect on loneliness, but an increased number of new relationships for participants at one and two years following intervention[12]. Fujiwara and colleagues investigated the effects of a social activity involving working with children in schools, finding that the intervention increased contact with participants' grandchildren and increased numbers of distant friends[13]. The intervention also reduced reliance on support received from friends and neighbours. The review found that those interventions offered at a group level were more likely to be beneficial compared with one-to-one interventions. The review concluded that well-conducted studies of the effectiveness of social interventions for alleviating social isolation are needed to improve the evidence base.

A 2011 Social Care Institute for Excellence research briefing regarding interventions to prevent loneliness and social isolation did not find any evidence involving interventions for new parents[14]. Likewise a 2011 meta-analysis of interventions to reduce loneliness found that the majority of participants were older adults and new parents did not appear amongst samples[15]. This meta-analysis did find that social support interventions reduce loneliness, indicating that the type of intervention suggested in this question has some research support in other populations.

Ongoing studies/ Trials in progress:

A systematic review registered on the PROSPERO database in 2014 is investigating the impact of physical and mental health of interventions aimed at increasing social capital among older people and would potentially include any relevant research that included both older people and new parents, although no such research has been located in searches conducted for this priority briefing. http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42014015362

How does this fit with PenCLAHRC research priority criteria?

Size of the health problem: Social isolation has a negative association with quality of life and wellbeing[15]. Being lonely has a significant and lasting effect on blood pressure, with lonely individuals having higher blood pressure than their less lonely peers[2]. Social isolation is also associated with depression and higher rates of mortality[16]. The influence of social relationships on the risk of death are comparable with well-established risk factors for mortality such as smoking and alcohol consumption and exceed the influence of physical activity and obesity[16]. Such negative impact on individuals' health leads to higher health and social care service use[17]. Much of the research indicates an association between social isolation and poor health, meaning that social isolation does not necessarily cause poor health, indeed ill health is amongst the groups at risk of social isolation.

Social isolation affects about 1 million older people, and has a severe impact on people's quality of life in older age[18]. For older people the onset of loneliness can happen gradually, sometimes preceded by a specific life event, especially one associated with loss, such as retirement, or bereavement[19]. Social networks may diminish in size in old age due to death or illness of previous contacts, or older people may be unable to take part in previously enjoyed activities due to their own ill health[20].

Feelings relating to new parenthood can range from pleasure and joy to anger, loneliness, and depression. In addition, single parents of newborns in many Western cultures report feeling isolated from other adults[21]. They are at increased risk of mood disorders such as depression and anxiety. Thus, their infants are vulnerable to early developmental deficits where parenting is affected[22]. Research from Barnado's reports that 61 per cent of British parents describe parenting as 'fairly' or 'very difficult' and 94 per cent of parents say it is helpful to talk to another person about parenting problems.

The potential for health improvement: The alleviation of loneliness and isolation has been recognised as a major priority for national and local government policy by some groups. Valtorta and Hanratty[23] state:

> *A drive to address loneliness and isolation could prove to be one of the most cost-effective strategies that a health system could adopt, and a counter to rising costs of caring for an ageing population* (p 521).

The role that social isolation plays as a risk factor for illnesses such as coronary heart disease is generally accepted. In addition, it can increase risks of falls and other injuries[24]. The benefits to individuals and society of reducing social isolation are therefore clear. Reducing social isolation also provides benefits to the wider community, for instance, through increased volunteering and caring responsibilities[17].

Interventions that treat chronic and long-term health conditions can lead to a decrease in loneliness[25]. It appears that group interventions are more effective than one-to-one support[14, 26].

Research suggests that social support interventions help lonely older people and new mothers, improving their wellbeing as well as increasing social contact (e.g.[10,11]). However, this type of intervention has not been tested with both populations together. Various systematic reviews also provide evidence of the benefits of parenting support programmes (e.g.[27]). Such reviews rarely include the small amount of research that involves older people in parenting support.

The practicality of the research question: The question posed seeks to investigate whether involving both older people and new parents in the same social support intervention is more beneficial to their wellbeing compared to a similar intervention that only includes one of the groups. There is a lack of theorising in the literature to support this hypothesis. Only one article was found that investigated an intervention involving both older people and new mothers[10]. In this article the authors contend that the benefits of the intervention for the mothers could be attributed to social contact with other mothers or reduction of social isolation generally, rather than the support provided by the older people involved in the intervention. When older individuals participate in parenting support, intergenerational differences in perceptions about child care and the potential negative impact on infants and the older individual's health would need to be considered[28].

Whether the South West is a good place to do this research: In 2013 the Office for National Statistics reported that the South West was the region with the highest proportion of older people. The rate of net migration of older people from other regions into the South West was also the highest among the regions of England. Challenges such as the rurality of the region, where two thirds of the 37 local authorities (62%) are predominantly rural, may impact the level of social isolation experienced. In regards to new parent populations, the total fertility rate in the South West is slightly higher than the national average.

Alignment with local health priorities: This will be different across the South West region and between organisations. Please consider the briefing in line with your local priorities.

GUIDELINES & GOVERNMENT STRATEGIES relating to this area:

Given the impact of social isolation on individual health and wellbeing, cost of care and wider community imperatives, there has been policy consensus that support must be provided to tackle social isolation and loneliness, particularly in the elderly[17].

Relevant Abstracts:

Kusano, E., Ono, M., & Hayakawa, K. (2010). Influence of support by elderly persons on Japanese mothers' child care-related stress. *Nursing & health sciences*, *12*(2), 182-190.

This study examined the influence of child-care support by elderly persons on mothers' child care-related stress in Japan. A cross-sectional study was conducted from February to April 2007 by using an anonymous questionnaire. This study focused on the "child-care salon" (hereafter referred to as "salon") as a type of parenting support activity by elderly persons in the community. For the analysis, 119 salon participants and a control group of 107 mothers who had not participated in a salon were recruited. As a result of a multiple regression analysis, participation or non-participation in the salon had no influence on the 'threat of loss of personal identity' stress, which was similar to a sense of social isolation because of child care. However, as a result of investigating the influence of the participation frequency on stress score for participants alone, mothers with less participation had a higher stress score than mothers with greater participation. That suggested the importance of intervention for a decrease of social isolation in mothers, especially in the initial stage of salon participation.

Dickens, A. P., Richards, S. H., Greaves, C. J., & Campbell, J. L. (2011). Interventions targeting social isolation in older people: a systematic review. *BMC public health, 11*(1), 647.

Background: Targeting social isolation in older people is a growing public health concern. The proportion of older people in society has increased in recent decades, and it is estimated that approximately 25% of the population will be aged 60 or above within the next 20 to 40 years. Social isolation is prevalent amongst older people and evidence indicates the detrimental effect that it can have on health and wellbeing. The aim of this review was to assess the effectiveness of interventions designed to alleviate social isolation and loneliness in older people.

Methods: Relevant electronic databases (MEDLINE, EMBASE, ASSIA, IBSS, PsycINFO, PubMed, DARE, Social Care Online, the Cochrane Library and CINAHL) were systematically searched using an extensive search strategy, for randomised controlled trials and quasi-experimental studies published in English before May 2009. Additional articles were identified through citation tracking. Studies were included if they related to older people, if the intervention aimed to alleviate social isolation and loneliness, if intervention participants were compared against inactive controls and, if treatment effects were reported. Two independent reviewers extracted data using a standardised form. Narrative synthesis and vote-counting methods were used to summarise and interpret study data.

Results: Thirty two studies were included in the review. There was evidence of substantial heterogeneity in the interventions delivered and the overall quality of included studies indicated a medium to high risk of bias. Across the three domains of social, mental and physical health, 79% of group-based interventions and 55% of one-to-one interventions reported at least one improved participant outcome. Over 80% of participatory interventions produced beneficial effects across the same domains, compared with 44% of those categorised as non-participatory. Of interventions categorised as having a theoretical basis, 87% reported beneficial effects across the three domains compared with 59% of interventions with no evident theoretical foundation. Regarding intervention type, 86% of those providing activities and 80% of those providing support resulted in improved participant outcomes, compared with 60% of home visiting and 25% of internet training interventions. Fifty eight percent of interventions that explicitly targeted socially isolated or lonely older people reported positive outcomes, compared with 80% of studies with no explicit targeting.

Conclusions: More, well-conducted studies of the effectiveness of social interventions for alleviating social isolation are needed to improve the evidence base. However, it appeared that common characteristics of effective interventions were those developed within the context of a theoretical basis, and those offering social activity and/or support within a group format. Interventions in which older people are active participants also appeared more likely to be effective. Future interventions incorporating all of these characteristics may therefore be more successful in targeting social isolation in older people.

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PRIORITY BRIEFING ID 2

The purpose of this briefing paper is to aid Stakeholders in prioritising topics to be taken further by PenCLAHRC as the basis for a specific evaluation or implementation research project. This paper was compiled in 2-3 days. The briefing is in four parts:

- General context
- The question in a structured format
- What the research evidence says
- Alignment with PenCLAHRC research priority criteria

QUESTION: Is Early Supported Discharge for stroke rehabilitation more effective when patients have clear expectations of their rehabilitation?

General context and definitions: 'Early Supported Discharge'(ESD) is a service for people after stroke which allows transfer of care from an inpatient environment to a primary care setting to continue rehabilitation, without changing the intensity or level of expertise of rehabilitation provision.

Stroke is a major cause of chronic disability worldwide. A priority within the NHS's accelerating stroke improvement programme is to ensure that 40% of all stroke survivors are provided with specialist ESD services from hospital[1]. ESD was initiated as part of the development of services that could accelerate the discharge of stroke patients admitted to hospital. It was hypothesised that such schemes could improve stroke care by providing a seamless service that spans the period of discharge home, a time that patients and carers frequently find difficult. Whilst a variety of ESD models exist, ESD has been shown to reduce hospital stay and improve patient functional capacity and satisfaction compared to conventional care. However, research also suggests that some ESD patients feel they have moved home too quickly and feel anxious and uncertain about being home. A number of recent studies have also highlighted that individuals can feel ill prepared to cope in the longer term and 'abandoned' by services, particularly after the period of acute care and rehabilitation has been completed. These factors may cause increased demands on rehabilitation and emergency services. Clearer expectations about rehabilitation may benefit those who receive ESD, and their carers, as well as reduce home rehabilitation costs.

The question in a structured format: In considering this as a research question, we could frame it as following:

Population:	People recently recovering from stroke receiving Early Supported Discharge (ESD) care
Intervention:	Clearer information regarding rehabilitation expectations (realistic goal setting, greater understanding for both stroke survivor and carer)
Comparator:	Usual ESD service
Outcomes of Interest:	Patient satisfaction, Carer burden, Re-referral rates, healthcare resource use

What the research evidence says: There is clear evidence about the benefit of ESD. One Cochrane review[2] and several systematic reviews have shown that ESD provided by a specialist multidisciplinary team leads to better clinical outcomes, increased satisfaction with care, reduced carer burden, and reduced NHS costs[3-5]. ESD is a core component of an evidence-based stroke service and is the current 'gold standard' for an early community rehabilitation service after stroke for people with ongoing rehabilitation needs who are discharged to their own homes[6].

Goal setting is widely recognized as an integral part of stroke rehabilitation and is recommended in the NICE guideline for stroke[6]. Goal setting is used to enhance patient motivation, adherence and autonomy, as well as improve satisfaction with rehabilitation. Goal setting does not however necessarily ensure that patients have a clear understanding of the purpose of goals, nor ensures that they have clear realistic expectations about their likely rehabilitation. A systematic review of goal setting for stroke rehabilitation showed positive effects on the patients' perceptions of participation and self-care ability and impacted positively on their performance and goal achievement [7]. However, patient-related barriers of goal setting included a lack of understanding of the rehabilitation process, and a lack of knowledge and understanding regarding the consequences of stroke and realistic outcomes.

There are several qualitative studies of patient experience of ESD. An interview study of ten participants in a large ongoing trial of ESD from Sweden[8] reported mixed expectations such as insecurity and fear, as well as a longing to come home. Whilst the participants had a high degree of confidence in the expected support of the ESD team, this was mixed with insecurity at being away from hospital care. The authors concluded that it would be beneficial to explore the patients' expectations thoroughly prior to discharge, as certain feelings and thoughts could complicate or support the home coming process. The authors also stated that a greater attention on such expectations may facilitate the transition from hospital to home after stroke. Taule and colleagues[9] interviewed eight stroke survivors who were receiving ESD as part of a Norwegian trial. A crucial determinant for the participants' hopes for a life worth living was the mutual confidence expressed in encounters with healthcare professionals and the participants' ability to make sense of their now-altered body. The authors concluded that help in processing the emotional reactions caused by a changed body and in socialising was essential for participants, and recommended that professional caretakers providing home rehabilitation should strive for a more flexible and individually tailored service. Cobley and colleagues[10] also report patient difficulties related to provision of information and support. In their UK study of 28 stroke survivors, whilst ESD was perceived positively by the users of the service, it was not without challenges which included: limited support in dealing with carer strain; lack of education and training of carers; inadequate provision and delivery of stroke-related information; and a disjointed transition between ESD and ongoing rehabilitation services.

Whilst recent qualitative evidence suggests there are issues related to poor understanding and information provision, whether having clearer expectations about post-stroke issues and rehabilitation progress would improve patient and carer quality of life, as well as reduce potentially unnecessary contact with health resources, has not been researched.

Ongoing studies/ Trials in progress: No ongoing studies assessing or addressing expectations, or improving provision of information and communication for ESD for recent stroke survivors were found.

How does this fit with PenCLAHRC research priority criteria?

Size of the health problem: Stroke is a major health problem in the UK. Each year, approximately 110,000 people in England, 11,000 people in Wales and 4,000 people in Northern Ireland have a first or recurrent stroke. Most people survive a first stroke but often have significant morbidity. More than 900,000 people in England are living with the effects of stroke[6]. In England, stroke is estimated to cost the economy around £9 billion per year. This comprises direct costs to the NHS of £4.4 billion, costs of informal care of £2.4 billion and costs because of lost productivity and disability of £2.1 billion[11].

The potential for health improvement: Stroke is the largest cause of complex disability - half of all stroke survivors are left with a disability[12]. Over a third of stroke survivors in England, Wales and Northern Ireland are discharged from hospital requiring help with activities of daily living. In the Stroke Association survey of over 2000 stroke survivors recently discharged home (not specifically ESD), 43% wanted more therapy support once discharged home, and 18% felt they had access to care services reduced or withdrawn, despite their needs increasing or remaining the same[13]. In the same survey, 85% of thought those they came into contact with did not understand stroke. Fatigue, depression and feeling overwhelmed are also common experience. Greater communication pre-discharge, ensuring the patient and carer understand the forthcoming rehabilitation progress and have adequate access to regular information and support could help to alleviate many of these issues.

The practicality of the research question: ESD is not available everywhere in the UK. In 2014, it was estimated that 66% of hospitals have access to ESD services (Stroke Association, 2015). Exploring ways to improve expectations and understanding is feasible if the ESD team are available and willing.

Whether the South West is a good place to do this research: There is variation in access to ESD services across the region. There may be some areas (those currently without ESD services, or those with ESD services but interested in new approaches) within the region that would be interested and willing to focus on patient and carer expectations and assess what impact this might have.

Alignment with local health priorities: This will be different across the South West region and between organisations. Please consider the briefing in line with your local priorities.

GUIDELINES & GOVERNMENT STRATEGIES relating to this area:

Department of Health (2007). *National Stroke Strategy*. London: Department of Health

National Institute for Health and Care Excellence (2010). *Stroke in Adults: Quality Standard*. National Institute for Health and Care Excellence. (update due April 2016)

National Institute for Health and Care Excellence (2013). *Stroke Rehabilitation in Adults.* NICE Clinical Guideline, National Institute for Health and Care Excellence.

‘Expectations’ does not feature in this NICE guideline. There is guidance that specifies the need for individualised goal setting, and that the goals need to be meaningful, challenging but achievable, and both short and long term. Goal setting needs to have active involvement of the person with stroke and they should have accessible information and support to help in setting goals. There is also guidance specific to the provision of information more generally. The guidance recommends the rehabilitation team should when working with the person with stroke and their family/carer ‘identify their information needs and how to deliver them, taking into account specific impairments such as aphasia and cognitive impairments. Pace the information to the person's emotional adjustment’.

SIGN (2010). *Management of patients with stroke: rehabilitation, prevention and management of complications, and discharge planning. A National Clinical Guideline*. Scottish Intercollegiate Guidelines Network.

As per the NICE guideline, there is guidance related to agreed achievable goal setting, but no general guidance relating to assessing or managing expectations. There is only one mention of expectations: ‘It is important for the social worker to be aware of the patient’s own goals and expectations’.

Relevant Abstracts:

Nordin Å, Sunnerhagen KS, Axelsson ÅB. Patients' expectations of coming home with Very Early Supported Discharge and home rehabilitation after stroke - an interview study. BMC Neurol. 2015 Nov 16;15(1):235.

BACKGROUND: An Early Supported Discharge (ESD) and rehabilitation from a coordinated team in the home environment is recommended in several high-income countries for patients with mild to moderate symptoms after stroke. Returning home from the hospital takes place very early in Sweden today (12 days post stroke), thus the term Very Early Supported Discharge (VESD) is used in the current study. The aim of this study was to describe patients' expectations of coming home very early after stroke with support and rehabilitations at home. **METHOD:** This is an interview study nested within a randomized controlled trial; Gothenburg Very Early Supported Discharge (GOTVED), comparing VESD containing a home rehabilitation intervention from a coordinated team to conventional care after stroke. Ten participants (median age 69) with mild to moderate stroke symptoms (NHISS 0 to 8 points) were recruited from the intervention group in GOTVED. Interviews were conducted 0-5 days before discharge and the material was analyzed with qualitative content analysis. **RESULTS:** Four main categories containing 11 subcategories were found. The VESD team was expected to provide "Support towards independency", by helping the participants to manage and feel safe at home as well as to regain earlier abilities. The very early discharge gave rise to expectations of coming home to "A new and unknown situation", causing worries not to manage at home and to leave the safe environment at the ward. A fear to suffer a recurrent stroke when being out of reach of immediate professional help was also pronounced. In contrast to these feelings of insecurity and fear, "Returning to one's own setting" described the participants longing home, where they would become autonomous and capable people again. They expected this to facilitate recovery and rehabilitation. "A new everyday life" waited for the participants at home and this was expected to be challenging. Different strategies to deal with these challenges were described. **CONCLUSIONS:** The participants described mixed expectations such as insecurity and fear, and on the other hand, longing to come home. Moreover, they had a high degree of confidence in the expected support of the VESD team. The health professionals at the hospital may build on this trust to reduce the patients' insecurity for coming home. In addition, it may be beneficial to explore the patients' expectations thoroughly in front of discharge, as certain feelings and thoughts could complicate or support the home coming process. Thus, a greater attention on such expectations may facilitate the patient's transition from hospital to home after stroke.

Taule, T., Strand, L. I., Skouen, J. S., & Raheim, M. (2015). Striving for a life worth living: Stroke survivors' experiences of home rehabilitation. Scandinavian Journal of Caring Sciences (Epub ahead of print)

Abstract: Background For mild-to-moderate stroke survivors, early supported discharge from hospital, followed by home rehabilitation is preferred over conventional care. How this mode of service contributes to recovery from stroke survivors' perspective needs further investigation. Aim The aim of this study was to explore mild-to-moderate stroke survivors' experiences with home rehabilitation after early supported discharge from hospital. Methods A qualitative interpretive interview design was used in the context of a randomised controlled trial. A purposive sample of eight participants (45-80 years) was followed by an ambulant team, and a specific healthcare team provided home rehabilitation. Data were analysed using interpretive description, systematic text condensation and coping theory. Findings A crucial determinant for the participants' hopes for a life worth living was the mutual confidence expressed in encounters with healthcare professionals and the participants' ability to make sense of their now-altered body. The professional caretakers' communication qualities and their ability to attend to individual needs were important. Help in processing the emotional reactions caused by a changed body and in socialising was requested by participants. Professional caretakers providing home rehabilitation should strive for a more flexible- and individually tailored service and should seek increased cooperation among stakeholders. Conclusion The focus on therapeutic communicative qualities, bodily changes, emotional processes, social concerns and long-term follow-up should be increased in order to achieve a more beneficial experience for stroke survivors.

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PRIORITY BRIEFING ID 3

The purpose of this briefing paper is to aid Stakeholders in prioritising topics to be taken further by PenCLAHRC as the basis for a specific evaluation or implementation research project. This paper was compiled in 2-3 days. The briefing is in four parts:

- General context
- The question in a structured format
- What the research evidence says
- Alignment with PenCLAHRC research priority criteria

QUESTION: Are brain training apps effective in improving cognition post stroke?

General context and definitions: Stroke is one of the leading causes of disability and death worldwide. More than half of people with stroke experience a combination of physical, functional and cognitive impairments and many require intensive rehabilitation[1]. The prevalence of cognitive impairment in stroke survivors is high and patients may present general cognitive deficits (e.g. slower information processing) or impairments within specific cognitive domains (e.g. memory, attention, executive function, language). Such impairments in cognitive functioning can substantially affect daily living activities and functional recovery[2]. Cognitive rehabilitation is recommended as an integral part of stroke rehabilitation. This aims to restore function or compensate for lost function to assist adaptation and facilitate independence. The field of cognitive rehabilitation is still in development and brain training apps are gaining popularity as a method to promote cognitive function through repeated cognitive exercises.

Apps are software programmes that have been developed to run on a computer or mobile device to accomplish a specific purpose[3]. Their usability and availability gives the option to independently improve memory or problem-solving skills which can be a key motivator for users. If brain training apps prove to be effective in improving cognition in the context of stroke, this could reduce expensive assistive therapy interventions and potentially save costs. However, little is currently known about the use of brain training apps in stroke rehabilitation care. Other forms of computer-based cognitive training interventions such as those using commercial game consoles and virtual reality environments have been studied within stroke rehabilitation, and their effectiveness remains controversial[4,5].

The question in a structured format: In considering this as a research question, we could frame it as following:

Population:	People with identified cognitive difficulties as a result of stroke
Intervention:	An intervention based on software applications (i.e. apps) which is targeted at improving (components of) cognitive function post stroke
Comparator:	No apps; standard care
Outcomes of Interest:	Global cognition; specific cognitive domains

What the research evidence says: A 2012 randomised controlled trial showed that playing a brain training game for 4 weeks could lead to improved processing speed and executive functions in older adults, but relevance for everyday functioning is unclear[6]. Although there are multiple studies of cognitive training and cognitive rehabilitation interventions after stroke[4,5,7], our searches did not identify any evidence for the effectiveness of post-stroke brain training apps using mobile devices such as smartphones and tablets. Research in other types of computer-assisted interventions has mainly focussed on sensory and motor impairments. Evidence for the effectiveness of cognitive rehabilitation using interactive video games or other virtual reality environments in people with stroke remains equivocal[4,5].

A systematic review and meta-analysis published in 2013 on the effectiveness of computer-based cognitive rehabilitation on cognitive improvement in patients with stroke identified 12 studies including seven small randomised trials[4]. Each study used simulator-based training of variable treatment sessions and duration but none was clearly identified as an app. The review meta-analysed eight of the included studies and concluded that computer-based cognitive rehabilitation programmes are “moderately effective” in improving cognitive function after stroke (effect size: 0.54, 95% CI: 0.33-0.74). However, the results were based on a limited number of high-quality studies, did not extend to specific cognitive domains and did not take account of age, stroke severity or pre-stroke computer literacy.

A Cochrane review published in the same year focussed on the effects of cognitive rehabilitation on executive dysfunction in adults with stroke or other non-progressive acquired brain injuries. Executive functions are the controlling mechanism of the brain; they are essential for goal-oriented behaviour and include the processes of planning, initiation, inhibition and problem-solving. The review identified 19 randomised trials, of which seven studies investigated the effect of computerised cognitive training packages. The authors concluded there was insufficient high-quality evidence to reach any generalised conclusions about the effect of cognitive rehabilitation on executive function or its components. Further research with the inclusion of comparison groups with no intervention, placebo or sensorimotor interventions was also recommended.[5] Another recent Cochrane review examined the effectiveness of virtual reality for stroke rehabilitation, including cognitive function as a secondary outcome. However, after searching the literature up to November 2013 the authors were unable to identify any trials which examined effects on cognition[8].

Ongoing studies/ Trials in progress: No ongoing trials were identified for the effect of brain training apps on cognition post stroke. In broader terms of computer-based rehabilitation, one related trial is in progress: NCT01886183. It is a prospective, single blinded, randomized clinical trial in 40 chronic stroke patients. The trial will compare the effects of two balanced training programmes, one Nintendo Wii fit-based (20 patients) and the other without the use of a gaming system (20 patients) on cognition among other primary outcomes (https://clinicaltrials. gov/ show/NCT01886183).

How does this fit with PenCLAHRC research priority criteria?

Size of the health problem: Stroke is the fourth single largest cause of death in the UK and second in the world. There are approximately 152,000 cases of stroke annually and it is estimated that more than 1.2 million stroke survivors are living in the UK[9]. About half of stroke survivors will have a disability mostly in the physical domain but a high prevalence of cognitive impairment ranging from 11% to 58% has been reported across community and hospital studies[10]. Moreover, stroke is associated with vascular and mixed dementia which may cause deficits in processing speed, planning, and problem-solving but also memory and language difficulties[11].

The potential for health improvement: Given the high proportion of stroke survivors having some form of cognitive impairment and its effects on recovery, post stroke cognitive improvements may have wide beneficial effects on patients, carers and the healthcare system. The increasing usability and availability of apps, along with the opportunity for self-managing rehabilitation through this medium would be an additional advantage for some users. However, brain training app development for stroke survivors is still in its infancy and there is insufficient evidence to estimate its effectiveness on cognition. According to the authors, the findings of the meta-analysis described earlier[4] suggest a clinically meaningful effect size of computer-based programmes in cognitive rehabilitation for patients with stroke, comparable to strength training and constraint-induced movement therapy to improve physical function (effect sizes 0.21 and 0.44 respectively). It remains to be seen whether such findings will be replicated in the case of apps.

The practicality of the research question: This question requires primary research involving the development of a relevant app and feasibility testing with stroke survivors. Well-designed high quality studies are also required to estimate the effectiveness of other types of software applications currently investigated for their use in cognitive rehabilitation after stroke.

Whether the South West is a good place to do this research: Age is one of the most important risk factors for stroke, and the risk doubles every decade after the age of 55[10]. The South West Peninsula has an older population than the England average. According to the Projecting Older People Population Information System, by the Institute for Public Care and Oxford Brooks University (www.poppi.org.uk), in 2014 there were over 1.14 million people aged over 65 living in the South West, of which 165,000 are aged over 85, a third of which are aged over 90. It is estimated that by 2025, there will be a 25% increase in people aged over 65, and a 50% increase in those aged over 90. There is also a strong stroke service locally and research investigating the effectiveness of a physical rehabilitation programme for stroke survivors is in progress with the CLAHRC (e.g. ReTrain project: http://clahrc-peninsula.nihr.ac.uk/research/retrain). There have also been projects developing apps for diabetes self-management (http://clahrc-peninsula.nihr.ac.uk/research/diabetes-app) and dementia assessment (http://clahrc-peninsula.nihr.ac.uk/research/neurocore).

Alignment with local health priorities: This will be different across the South West region and between organisations. Please consider the briefing in line with your local priorities.

GUIDELINES & GOVERNMENT STRATEGIES relating to this area:

NICE published clinical guidelines in June 2013 – Stroke rehabilitation in adults[12]. The guidelines describe key aspects of rehabilitation care that cover multidisciplinary assessment, identification of functional difficulties and their measurement, treatment planning and delivery of interventions. For cognition, the understanding of cognitive strengths and weaknesses of people with stroke through detailed cognitive assessment is emphasised as a central part of rehabilitation. Recommendations also cover general types of interventions and techniques that should take place as part of the cognitive rehabilitation plan in the areas of memory, attention and visual neglect but without providing information for specific tools to facilitate this process. Guidance also includes the provision of education and support for people with stroke, their families and carers to help them understand the impact and extent of post stroke cognitive impairment.

The National clinical guideline for stroke was prepared by the Intercollegiate Stroke Working Party and published in September 2012[1]. The guideline contains recommendations that cover every aspect of stroke management including general principles for post stroke cognitive impairment. More specific recommendations for particular cognitive domains including memory, attention and concentration, executive functioning, spatial awareness, and perception are also provided. The report also outlines standardised measures for cognitive assessment, techniques and goals or steps to be followed within a structured rehabilitation plan.

Relevant Abstracts:

Cha, Yu-Jin, and Hee Kim. "Effect of computer-based cognitive rehabilitation (CBCR) for people with stroke: a systematic review and meta-analysis." ***NeuroRehabilitation*** **(2012), 32,2: 359-368.**

OBJECTIVE: We conducted a systematic review and meta-analysis to identify the effect of computer-based cognitive rehabilitation (CBCR) on improving cognitive functions in patients with stroke. METHODS: Researchers performed a literature search using computerized databases such as the Cochrane Database, EBSCO (CINAHL), PsycINFO, PubMed and Web of Science. The following keywords were used: stroke, computer-based, cognitive rehabilitation, and others. The methodological quality was evaluated. Statistical heterogeneity and standardized mean difference were used to compute the overall effect size and that of subgroups. Also publication bias of the selected studies was analysed. RESULTS: Twelve studies met the inclusion criteria including a total of 461 stroke survivors. Among studies, six RCT studies were rated as high methodological quality. Overall effect size was medium 0.54, and the 95 % confidence interval was 0.33–0.74. The effect sizes of acute and chronic phase of stroke were both 0.54. They can be interpreted as medium effect size and were statistically significant. The statistical heterogeneity and publication bias were not significant. CONCLUSION: The present study provides evidence that CBCR is effective on improving cognitive function after stroke. We recommend conducting meta-analysis on subgroups of CBCR programs in further studies.

Chung Charlie, SY, Pollock, A, Campbell, T, Durward Brian, R, Hagen, S. Cognitive rehabilitation for executive dysfunction in adults with stroke or other adult non-progressive acquired brain damage. ***Cochrane Database of Systematic Reviews,*** **2013.**

Background: Executive functions are the controlling mechanisms of the brain and include the processes of planning, initiation, organisation, inhibition, problem solving, self-monitoring and error correction. They are essential for goal-oriented behaviour and responding to new and novel situations. A high number of people with acquired brain injury, including around 75% of stroke survivors, will experience executive dysfunction. Executive dysfunction reduces capacity to regain independence in activities of daily living (ADL), particularly when alternative movement strategies are necessary to compensate for limb weakness. Improving executive function may lead to increased independence with ADL. There are various cognitive rehabilitation strategies for training executive function used within clinical practice and it is necessary to determine the effectiveness of these interventions.

Objectives: To determine the effects of cognitive rehabilitation on executive dysfunction for adults with stroke or other non-progressive acquired brain injuries.Search methods: We searched the Cochrane Stroke Group Trials Register (August 2012), the Cochrane Central Register of Controlled Trials (The Cochrane Library, August 2012), MEDLINE (1950 to August 2012), EMBASE (1980 to August 2012), CINAHL (1982 to August 2012), PsycINFO (1806 to August 2012), AMED (1985 to August 2012) and 11 additional databases. We also searched reference lists and trials registers, hand searched journals and conference proceedings, and contacted experts. Selection criteria: We included randomised trials in adults after non-progressive acquired brain injury, where the intervention was specifically targeted at improving cognition including separable executive function data (restorative interventions), where the intervention was aimed at training participants in methods to compensate for lost executive function (compensative interventions) or where the intervention involved the training in the use of an adaptive technique for improving independence with ADL (adaptive interventions). The primary outcome was global executive function and the secondary outcomes were specific components of executive function, working memory, ADL, extended ADL, quality of life and participation in vocational activities. We included studies in which the comparison intervention was no treatment, a placebo intervention (i.e. a rehabilitation intervention that should not impact on executive function), standard care or another cognitive rehabilitation intervention. Data collection and analysis: Two review authors independently screened abstracts, extracted data and appraised trials. We undertook an assessment of methodological quality for allocation concealment, blinding of outcome assessors, method of dealing with missing data and other potential sources of bias.

Main results: Nineteen studies (907 participants) met the inclusion criteria for this review. We included 13 studies (770 participants) in meta-analyses (417 traumatic brain injury, 304 stroke, 49 other acquired brain injury) reducing to 660 participants once non-included intervention groups were removed from three and four group studies. We were unable to obtain data from the remaining six studies. Three studies (134 participants) compared cognitive rehabilitation with sensorimotor therapy. None reported our primary outcome; data from one study was available relating to secondary outcomes including concept formation and ADL. Six studies (333 participants) compared cognitive rehabilitation with no treatment or placebo. None reported our primary outcome; data from four studies demonstrated no statistically significant effect of cognitive rehabilitation on secondary outcomes. Ten studies (448 participants) compared two different cognitive rehabilitation approaches. Two studies (82 participants) reported the primary outcome; no statistically significant effect was found. Data from eight studies demonstrated no statistically significant effect on the secondary outcomes. We explored the effect of restorative interventions (10 studies, 468 participants) and compensative interventions (four studies, 128 participants) and found no statistically significant effect compared with other interventions.

Authors' conclusions: We identified insufficient high-quality evidence to reach any generalised conclusions about the effect of cognitive rehabilitation on executive function, or other secondary outcome measures. Further high-quality research comparing cognitive rehabilitation with no intervention, placebo or sensorimotor interventions is recommended.

Laver, K, George, S, Thomas, S, Deutsch, JE, Crotty, M. Virtual reality for stroke rehabilitation: an abridged version of a Cochrane review. *European Journal of Physical & Rehabilitation Medicine*, 2015. 51(4): p. 497-506.

Background: Virtual reality and interactive video gaming have emerged as recent treatment approaches in stroke rehabilitation. In particular, commercial gaming consoles have been rapidly adopted in clinical settings. This is an update of a Cochrane Review published in 2011.

Objectives: Primary objective: To determine the efficacy of virtual reality compared with an alternative intervention or no intervention on upper limb function and activity. Secondary objective: To determine the efficacy of virtual reality compared with an alternative intervention or no intervention on: gait and balance activity, global motor function, cognitive function, activity limitation, participation restriction and quality of life, voxels or regions of interest identified via imaging, and adverse events. Additionally, we aimed to comment on the feasibility of virtual reality for use with stroke patients by reporting on patient eligibility criteria and recruitment. Search methods: We searched the Cochrane Stroke Group Trials Register (October 2013), the Cochrane Central Register of Controlled Trials (The Cochrane Library 2013, Issue 11), MEDLINE (1950 to November 2013), EMBASE (1980 to November 2013) and seven additional databases. We also searched trials registries and reference lists. Selection criteria: Randomised and quasi-randomised trials of virtual reality ("an advanced form of human-computer interface that allows the user to 'interact' with and become 'immersed' in a computer-generated environment in a naturalistic fashion") in adults after stroke. The primary outcome of interest was upper limb function and activity. Secondary outcomes included gait and balance function and activity, and global motor function. Data collection and analysis: Two review authors independently selected trials based on pre-defined inclusion criteria, extracted data and assessed risk of bias. A third review author moderated disagreements when required. The authors contacted investigators to obtain missing information.

Main results: We included 37 trials that involved 1019 participants. Study sample sizes were generally small and interventions varied. The risk of bias present in many studies was unclear due to poor reporting. Thus, while there are a large number of randomised controlled trials, the evidence remains 'low' or 'very low' quality when rated using the GRADE system. Control groups received no intervention or therapy based on a standard care approach. Intervention approaches in the included studies were predominantly designed to improve motor function rather than cognitive function or activity performance. The majority of participants were relatively young and more than one year post stroke. Primary outcome: results were statistically significant for upper limb function (standardised mean difference (SMD) 0.28, 95% confidence intervals (CI) 0.08 to 0.49 based on 12 studies with 397 participants). Secondary outcomes: there were no statistically significant effects for grip strength, gait speed or global motor function. Results were statistically significant for the activities of daily living (ADL) outcome (SMD 0.43, 95% CI 0.18 to 0.69 based on eight studies with 253 participants); however, we were unable to pool results for cognitive function, participation restriction, quality of life or imaging studies. There were few adverse events reported across studies and those reported were relatively mild. Studies that reported on eligibility rates showed that only 26% of participants screened were recruited.

Authors' conclusions: We found evidence that the use of virtual reality and interactive video gaming may be beneficial in improving upper limb function and ADL function when used as an adjunct to usual care (to increase overall therapy time) or when compared with the same dose of conventional therapy. There was insufficient evidence to reach conclusions about the effect of virtual reality and interactive video gaming on grip strength, gait speed or global motor function. It is unclear at present which characteristics of virtual reality are most important and it is unknown whether effects are sustained in the longer term.

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PRIORITY BRIEFING ID 23

The purpose of this briefing paper is to aid Stakeholders in prioritising topics to be taken further by PenCLAHRC as the basis for a specific evaluation or implementation research project. This paper was compiled in 2-3 days. The briefing is in four parts:

- General context
- The question in a structured format
- What the research evidence says
- Alignment with PenCLAHRC research priority criteria

QUESTION: Can provision of staff support or training improve the implementation of advanced care plans for people with dementia resident in care homes, and reduce hospital admissions?

General context and definitions: Advance care planning is a process of structured discussion between an individual and a professional carer which may include family and friends and generally leads to a statement of preferences for future treatment and care. Advance care planning is a key means of improving care for people nearing the end of life and of enabling better planning and provision of care to help them to live and die in the place and the manner of their choosing. The process of advance care planning in the UK includes making three main elements explicit - what an individual would like to happen, what they don't want to happen and who will speak for them. The use of advance care plans is widely encouraged to improve end of life care, but in practice decisions may not be adequately disseminated to influence care.

Several mechanisms have been proposed to help with the incorporation of advance care plans into everyday practice in care homes, including the Gold Standards Framework Care Home Training Programme (GSFCH) (http://www.goldstandardsframework.org.uk/), the Namaste Care Programme, and integrated care pathways such as the adapted Liverpool Care Pathway. The GSFCH is the most widely used training programme to improve end of life care in care homes in the UK. It is a system-based organisational approach, developed in 2004, to optimise the end of life care provided by generalists within a care home context. The programme aims to improve the organisation and quality of care for residents in the last years of life, to improve collaboration across boundaries and to reduce avoidable hospital admissions. To qualify for accreditation, care homes must undertake the full training programme over nine months, embed this into their homes for at least six months and then undertaken a rigorous accreditation process. Across the UK, 564 care homes have received the accreditation award and 237 of these have achieved re-accreditation status.

The question in a structured format: In considering this as a research question, we could frame it as following:

Population:	People with dementia resident in care homes
Intervention:	Provision of staff support or training in the use of advanced care plans
Comparator:	Usual care.
Outcomes of Interest:	Improved implementation of advanced care plans, reduced hospital admissions, carer satisfaction.

What the research evidence says: A recent systematic review of factors associated with initiation of advance care plans in dementia (not exclusive to those resident in care homes) identified the wide range of different perspectives that may be involved in initiating discussion of advance care plans in people with dementia. The authors concluded that early initiation of advance care planning in this population requires careful consideration of timing and family and patient receptiveness or reluctance[1]. A further systematic review of advanced care planning for people with dementia (again not exclusive to those resident in care homes) highlighted the following key themes:

- there is a point at which cognition decreases critically so that an advance care plan can no longer be made,
- factors present in family carers and professionals can influence decision making and the advance care planning process,
- advance care plans are affected by preferences for life sustaining treatments,
- advance care planning in dementia may differ from other illness groups and,
- there is a need for education relating to advance care planning[2].

A systematic review published in 2011 aimed to identify the impact of implementing end-of-life care policy with regard to the use of the GSFCH, the Liverpool Care Pathway (or an Integrated Care Pathway for the last days of life) and educational/training interventions to support the provision of end of life care within a UK care home context[3]. All comparative studies conducted within residential care facilities in the UK were eligible for inclusion. The authors identified eight articles, reporting on three non-analytical case series studies in a total of 64 care homes. The studies provide limited evidence of improvements in resident outcomes and in relation to staff recognising and meeting residents' needs for end of life care as a result of implementation of the interventions.

A series of quantitative evaluations of the GSFCH programme have reported positive findings in terms of improved collaborations between care home staff and health service practitioners, increased staff knowledge and enhanced confidence in discussing end of life care[4-7]. However, there are also suggestions within the literature of difficulties in implementation. Qualitative studies conducted with care home staff and other professionals involved in end of life provision report that staff were generally positive and optimistic that the training they received would result in better end of life care for residents but also highlight some issues in implementation. Staff spoke of improved communication, increased staff confidence in end of life care, increased access to specialist palliative care support, fostering choice for residents and increased awareness of residents who were dying and their needs. The studies also report considerable uncertainty of the value of advance care plans amongst professionals (from palliative care, primary care, dementia care services, social services, the voluntary sector and legal professionals); uncertainty about responsibilities in relation to advance care plans; difficulties in finding the right time to initiate discussions; anxiety about the staffs' ability to deliver patient choice; and confusion about the variety of different formats of advance care plan available[8].

Additional resource beyond the provision of training may be necessary for successful implementation of the GSFCH training on advance care plans in care homes[6,9,10]. A cluster randomised controlled trial that compared i) a high level of facilitation together with action learning for nurse managers ii) a high level of facilitation alone and iii) provision of training alone in 38 UK nursing homes, found a significant association between the level of facilitation and the nursing homes' successful completion of the training programme through to accreditation. The authors also called for national guidelines for the facilitation of the GSFCH to ensure consistent implementation and highlight the need for the facilitation component to be funded[11].

How does this fit with PenCLAHRC research priority criteria?

Size of the health problem: Many people with dementia will die in a care home; many others may be transferred to hospital unnecessarily at the end of life. There are approximately 600 care homes in the South West. In 2013, 21% of deaths in the England occurred in care homes; in the South West the proportion was slightly higher at 26.6%. A high proportion of these deaths will involve people with dementia.

The potential for health improvement: End of Life Care for people with dementia has been recognised as being sub-optimal in many studies[12-14], particularly in care homes. The Alzheimer's Society report 'My Life Until the End - Dying Well with Dementia' published in 2012, highlighted the need to improve end of life care for people with dementia and made recommendations in seven key areas. In relation to care homes, the report recommends that there should be more training for care home staff on dealing with end of life for people with dementia. This includes acting on plans for emergency care, advance care plans and advance decisions which have been put in place, and working with medical professionals to co-ordinate a good end of life experience[15].

The practicality of the research question: There is clearly variation within the care home community in knowledge of and confidence in implementing both discussions about end-of-life choices and the subsequent care involved in delivering patient choice. It may be possible to explore the most effective mechanisms to implement advance care planning and to improve understanding of the barriers to the successful provision of good end of life care for people with dementia.

Whether the South West is a good place to do this research: According to the Gold Standards Framework website, there are currently 94 accredited care homes within the South West. The CQC website suggests there are in the region of 600 care homes in the South West although whether the boundaries are comparable is unclear. There are increasing links between PenCLAHRC academics and the care home community in the South West.

Alignment with local health priorities: This will be different across the South West region and between organisations. Please consider the briefing in line with your local priorities.

GUIDELINES & GOVERNMENT STRATEGIES relating to this area:

The Department of Health policy paper 'The End of Life Care Strategy' published in 2008 recommends training to enable care home staff to carry out advance care planning for residents, with one anticipated outcome being reduction of inappropriate hospital admissions[16].

Relevant abstracts:

Kinley J, Froggatt K, Bennett MI. The effect of policy on end-of-life care practice within nursing care homes: a systematic review. Palliat Med. 2013 Mar;27(3):209-20.

BACKGROUND: The number of older people in the UK is increasing. A significant proportion of end of life care for this population is currently provided and will increasingly be provided within nursing care homes.

AIM: To identify the impact of implementing end of life care policy with regard to the use of the Gold Standards Framework in Care Homes programme, the Liverpool Care Pathway (or an Integrated Care Pathway) and educational/training interventions to support the provision of end of life care within nursing care homes within the UK.

DESIGN & DATA SOURCES:: Systematic literature review of published literature and reports. An electronic search was undertaken of five databases-Medline, CINAHL, EMBASE, Web of Science and the Cochrane library and websites of government and palliative care organisations for papers and reports published between 2000 to June 2010. The reference lists of studies that were retrieved for the detailed evaluation were hand-searched for any additional relevant citations.. Only studies that included comparative outcome data were eligible for inclusion.

RESULTS: Eight papers/reports, incorporating information from three studies were identified. Two studies reported on the implementation of the Gold Standards Framework in Care Homes programme and one the implementation of an Integrated Care Pathway for the last days of life. Improvements occurred in resident outcomes and in relation to staff recognising, managing and meeting residents needs for end of life care.

CONCLUSIONS: The studies provided limited evidence on improved outcomes following the implementation of these interventions. Further research is needed, both within the UK and internationally, that measures the process and impact of implementing these initiatives.

van der Steen JT, van Soest-Poortvliet MC, Hallie-Heierman M, Onwuteaka-Philipsen BD, Deliens L, de Boer ME, Van den Block L, vanUden N, Hertogh CM, de Vet HC. Factors associated with initiation of advance care planning in dementia: a systematic review. J Alzheimers Dis. 2014;40(3):743-57.

BACKGROUND: Planning ahead may be particularly relevant in dementia considering patients' cognitive decline and difficulty to predict the course of the dementia.

OBJECTIVE: To identify factors associated with initiation of advance care planning (ACP) regarding end-of-life issues in dementia.

METHODS: Systematic review of the PubMed, Embase, Cinahl, Psychinfo, and Cochrane databases until January 2013. We included articles reporting on empirical research, identifying factors related to initiation of ACP defined as starting a discussion, starting the decision making, or having a documented patient-written advance directive.

RESULTS: Of 4,647 unique articles, we assessed 178 as full-texts, and included 33. Most designs (64%) were qualitative; 42% limited to moderate to severe, and 6% to mild to moderate stages.

Perspectives varied: family (33%), professional caregivers (24%), patient (15%), or multiple (27%). A variety of factors with complex interplay was involved in initiating ACP. Family factors dominated, with family's initiative or lack of it, and willingness or reluctance to engage in initiating ACP identified in a series of studies. Further, professional caregivers' initiative or lack of it and patient's health status were important factors that facilitated or hindered initiating ACP. Ethnic minority status of those involved and family distance may be barriers. Continuity of care and health care system factors also affected initiating of ACP.

CONCLUSION: Professional caregivers may initiate ACP early if strategies carefully consider timing and family and patient receptiveness or reluctance, and are family and patient-centered. Interventions should address the complexity of interrelated system and personal factors affecting initiation of ACP.

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PRIORITY BRIEFING ID 40

The purpose of this briefing paper is to aid Stakeholders in prioritising topics to be taken further by PenCLAHRC as the basis for a specific evaluation or implementation research project. This paper was compiled in 2-3 days. The briefing is in four parts:

- General context
- The question in a structured format
- What the research evidence says
- Alignment with PenCLAHRC research priority criteria

QUESTION: Is mindfulness based cognitive behaviour therapy effective in maintaining recovery and relapse prevention among young people who have recovered from an episode of emotional disorder?

General context and definitions: Mindfulness-based Cognitive Therapy (MBCT) combines aspects of cognitive behavioural therapy with training in meditation. MBCT is a class-based intervention which teaches people skills that enable them to become more aware of their thoughts without judgment, viewing negative (positive and neutral) thoughts as passing mental events rather than as facts[1]. MBCT may help people learn to recognise habitual ways of thinking and behaving that signal worsening in their condition and can choose instead to respond adaptively[2]. The term emotional disorder is not a formal diagnosis, but usually refers to disorders characterised by feelings of intense internal and/or emotional distress that last intermittently or continually for months or years. Most often, it means that the individual has a diagnosis of a mood disorder or anxiety disorder[3], so would include generalized anxiety disorder, panic disorder, social anxiety disorder, specific phobias, depression, bipolar disorder, and cyclothymic disorder[4].

NICE guidelines for depression assume “young people” refers to individuals aged between 12 and 18. Child and Adolescent Mental Health Services referrals for depression have risen rapidly in recent years, with many young people having repeated episodes. Adolescence is the peak onset for depression and young people pay a heavy developmental price as school work and key relationships can be disrupted as a result[5]. Although substantial progress has been made in the treatment of many chronic mental health conditions, recurrent depression continues to cause significant disability and human suffering. Depression typically runs a relapsing and recurrent course , and this pattern may run throughout life, even after successful acute treatment[2]. The current mainstay approach to preventing depressive relapse is maintenance antidepressant medication, although many patient groups also advocate psychosocial approaches to help people at risk for depression or relapse[6].

The question in a structured format: In considering this as a research question, we could frame it as following:

Population:	Young people (12-18 years) who have responded to treatment for an emotional disorder
Intervention:	Mindfulness based cognitive behaviour therapy adapted for this age group
Comparator:	Treatment as usual (which may be maintenance on antidepressants)
Outcomes of Interest:	Longer time to relapse, fewer relapses and prompter recovery from relapse

What the research evidence says: A 2011 systematic review investigated the effect of MBCT for prevention of relapse or recurrence among *adult* patients with recurrent major depressive disorder in remission. It located six relevant randomized controlled trials (RCTs) with a total of 593 participants. The meta-analysis found that for patients with three or more previous depressive episodes MBCT was associated with a 44% reduction in the risk of depressive relapse compared with usual care. It also found that MBCT provides effects comparable with staying on a maintenance dose of antidepressants[7]. However, participants in the included trials had a mean age of 46 and none included young people. Since this systematic review there have been several more RCTs which have provided further evidence of the effectiveness of MBCT for prevention of relapse or recurrence among adults with prior or residual depressive symptoms[8-10]. While much focus to date has been on participants with depression, there is also evidence for MBCT's effectiveness in relapse prevention for adult bipolar disorder[1] and substance abuse[11].

Work with adults in the field of mindfulness is well developed with a convincing evidence base, but work with young people, is in its relative infancy[12]. A 2015 systematic review and meta-analysis examined the effects of different mindfulness-based interventions (not just MBCT) on mental health symptoms and quality of life in both clinical and non-clinical samples (not diagnosed or showing symptoms of mental health conditions) of children and adolescents[13]. It found that MBCT was more effective than non-active control groups in the non-clinical populations and drew the overall conclusion that mindfulness-based interventions appear useful in improving feelings of stress, anxiety, and depressive symptoms. The review however, was not focused on relapse.

A Cochrane systematic review published in 2012 aimed to determine the efficacy of interventions, including psychological and pharmacological treatments, to prevent relapse or recurrence of depressive disorders in children and adolescents[14]. The review authors noted that despite MBCT being identified as an effective relapse prevention treatment for depression in adults, no trials had been carried out in children and adolescents and therefore they were unable to draw any conclusions about the potential benefits of MBCT for young people. While there was some evidence for other psychological therapies, the authors still recommended more trials with larger sample sizes need to be conducted in order to explore non-pharmacological treatment approaches further.

The most relevant primary research to the submitted question is a 2014 pilot study which investigated the use of MBCT with young people (aged 12–18)[15], who had previously received psychological treatment for a mood disorder or low mood alongside an anxiety disorder, but continued to present with residual symptoms of depression. The study found high levels of satisfaction with the programme and indicated reductions in depressive symptoms, alongside positive change in mindfulness skills, quality of life and rumination. However, the low number (n=11) of participants; the absence of a control group or full assessment of non-completers; and lack of long-term follow-up means there is a gap for research investigating the use of MBCT for relapse of emotional disorders in young people.

In conclusion, evidence suggests that for adults MBCT is a cost-effective prevention programme that helps people with recurrent depression stay well in the long-term. It has been recommended as a treatment in National Institute for Health and Care Excellence (NICE) Guidelines since 2004 for adults with depression who are considered to be at significant risk of relapse or who have residual symptoms. It was singled out in the 2009 NICE Depression Guideline as a key priority for implementation in adult treatment. Research investigating MBCT's cost-effectiveness as a prevention programme for young people is lacking.

Ongoing studies/ Trials in progress:

We did not locate any ongoing studies or trials in progress.

How does this fit with PenCLAHRC research priority criteria?

Size of the health problem: Mental health problems in children and young people are common and account for a significant proportion of the burden of ill health in this age range. Depression in young people is common worldwide, rising to 4-8% of adolescents[16], but is often unrecognised. In a 2007 survey of adults in England, in the 16–24-year-old age group 2.2% experienced a depressive episode and 16.4% experienced anxiety disorder[17]. Adolescence is the peak onset for emotional disorders and young people pay a heavy developmental price as school work and key relationships can be disrupted as a result[5]. Figures from 2004 indicate the wider impact of emotional disorders for young people[18]: Surveys of teachers indicate that 17% of those with emotional disorders had missed more than 16 days of school in the last term. Among young people with an emotional disorder, 28% said they had tried to harm or kill themselves.

The potential for health improvement: Although most episodes of depression in children and adolescents last less than nine months, around half of young people will relapse within two months of initial improvement. Furthermore, depression recurs (that is a new bout of depression begins) in 70 % of children and adolescents over five years[16]. Given that MBCT appears effective in other populations, this indicates the potential for health improvement by focusing on relapse and maintaining recovery in children and young people.

The practicality of the research question: MBCT has a small but growing evidence base in relapse prevention among adults with depression, and there is a great deal of interest in mindfulness currently. The research question appears practical, given that research with adults indicates the effectiveness of the treatment. There is a need for further research on relapse treatment for children and young people which the research question would respond to. There are also adapted MBCT programmes for children and young people which have been used for treatment of ongoing anxiety (Cotton et al. 2015) and more broadly for young people in non-clinical samples[19]. Previous research suggests willingness from young people and their carers to engage in mindfulness[12]. Mindfulness links with concerns to reduce the burden of health spending on physical and mental illness, including stress and chronic conditions, through preventive, low cost, population based interventions[12].

Whether the South West is a good place to do this research: Mindfulness has been an important part of the University of Exeter since 2004 and work there involves training, research and clinical practice. In the South West there is expertise in training mindfulness practitioners, including at the University of Exeter and Mindfulness Cornwall. There is also expertise in treatment for adults, including Outlook South West whose mindfulness service is part of the national Improving Access to

Psychological Therapies (IAPT) programme, and treatment for young people and their carers in Devon CAMHS.

Alignment with local health priorities: This will be different across the South West region and between organisations. Please consider the briefing in line with your local priorities.

GUIDELINES relating to this area:

NICE guidelines on the identification and management of depression in children and young people do not include recommendations for the use of MBCT. Adult guidelines do recommend MBCT for adults who are currently well but have experienced three or more previous episodes of depression.

NICE (2009). Depression in adults: recognition and management. www.nice.org.uk/guidance/cg90

Relevant Abstracts:

Cox, G. R., Fisher, C. A., De Silva, S., Phelan, M., Akinwale, O. P., Simmons, M. B., & Hetrick, S. E. (2012). Interventions for preventing relapse and recurrence of a depressive disorder in children and adolescents. *The Cochrane Library*.

Depressive disorders often begin during childhood or adolescence. There is a growing body of evidence supporting effective treatments during the acute phase of a depressive disorder. However, little is known about treatments for preventing relapse or recurrence of depression once an individual has achieved remission or recovery from their symptoms.

Objectives: To determine the efficacy of early interventions, including psychological and pharmacological interventions, to prevent relapse or recurrence of depressive disorders in children and adolescents.

We searched the Cochrane Depression, Anxiety and Neurosis Review Group's Specialised Register (CCDANCTR) (to 1 June 2011). The CCDANCTR contains reports of relevant randomised controlled trials from The Cochrane Library (all years), EMBASE (1974 to date), MEDLINE (1950 to date) and PsycINFO (1967 to date). In addition we handsearched the references of all included studies and review articles.

Selection criteria: Randomised controlled trials using a psychological or pharmacological intervention, with the aim of preventing relapse or recurrence from an episode of major depressive disorder (MDD) or dysthymic disorder (DD) in children and adolescents were included. Participants were required to have been diagnosed with MDD or DD according to DSM or ICD criteria, using a standardised and validated assessment tool.

Two review authors independently assessed all trials for inclusion in the review, extracted trial and outcome data, and assessed trial quality. Results for dichotomous outcomes are expressed as odds ratio and continuous measures as mean difference or standardised mean difference. We combined results using random-effects meta-analyses, with 95% confidence intervals. We contacted lead authors of included trials and requested additional data where possible.

Nine trials with 882 participants were included in the review. In five trials the outcome assessors were blind to the participants' intervention condition and in the remainder of trials it was unclear. In the majority of trials, participants were either not blind to their intervention condition, or it was unclear whether they were or not. Allocation concealment was also unclear in the majority of trials. Although all trials treated participants in an outpatient setting, the designs implemented in trials was diverse, which limits the generalisability of the results. Three trials indicated participants treated with antidepressant medication had lower relapse-recurrence rates (40.9%) compared to those treated with placebo (66.6%) during a relapse prevention phase (odds ratio (OR) 0.34; 95%confidence interval (CI) 0.18 to 0.64, P =

0.02). One trial that compared a combination of psychological therapy and medication to medication alone favoured a combination approach over medication alone, however this result did not reach statistical significance (OR 0.26; 95% CI 0.06 to 1.15). The majority of trials that involved antidepressant medication reported adverse events including suicide-related behaviours. However, there were not enough data to show which treatment approach results in the most favourable adverse event profile.

Currently, there is little evidence to conclude which type of treatment approach is most effective in preventing relapse or recurrence of depressive episodes in children and adolescents. Limited trials found that antidepressant medication reduces the chance of relapse recurrence in the future, however, there is considerable diversity in the design of trials, making it difficult to compare outcomes across studies. Some of the research involving psychological therapies is encouraging, however at present more trials with larger sample sizes need to be conducted in order to explore this treatment approach further.

Ames, C. S., Richardson, J., Payne, S., Smith, P., & Leigh, E. (2014). Mindfulness-based cognitive therapy for depression in adolescents. *Child and Adolescent Mental Health*, *19*(1), 74-78.

Mindfulness-Based Cognitive Therapy (MBCT) has been shown to be effective in preventing relapse of depression in adults, but has not previously been applied to adolescents who have residual symptoms of depression following treatment.

An 8-week MBCT group was adapted for adolescents, and evaluated using qualitative and quantitative measures.

Participants report high levels of satisfaction with the group intervention. Qualitative analysis of semi-structured interviews provides areas for future development of this intervention. Pilot data indicate reductions in depressive symptoms, alongside positive change in mindfulness skills, quality of life and rumination.

Preliminary evidence for the use of MBCT with this group of adolescents is provided.

Piet, J., & Hougaard, E. (2011). The effect of mindfulness-based cognitive therapy for prevention of relapse in recurrent major depressive disorder: a systematic review and meta-analysis. *Clinical psychology review*, *31*(6), 1032-1040.

Mindfulness-based cognitive therapy (MBCT) is a group-based clinical intervention program designed to reduce relapse or recurrence of major depressive disorder (MDD) by means of systematic training in mindfulness meditation combined with cognitive-behavioral methods.

By means of a meta-analysis to evaluate the effect of MBCT for prevention of relapse or recurrence among patients with recurrent MDD in remission.

Electronic databases were searched and researchers were contacted for further relevant studies. Studies were coded for quality. Meta-analyses were performed by means of the Cochrane Collaboration Review Manager 5.1.

Six randomized controlled trials with a total of 593 participants were included in the meta-analysis. MBCT significantly reduced the risk of relapse/recurrence with a risk ratio of 0.66 for MBCT compared to treatment as usual or placebo controls, corresponding to a relative risk reduction of 34%. In a pre-planned subgroup analysis the relative risk reduction was 43% for participants with three or more previous episodes, while no risk reduction was found for participants with only two episodes. In two studies, MBCT was at least as effective as maintenance antidepressant medication.

Results of this meta-analysis indicate that MBCT is an effective intervention for relapse prevention in patients with recurrent MDD in remission, at least in case of three or more previous MDD episodes.

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PRIORITY BRIEFING ID 44

The purpose of this briefing paper is to aid Stakeholders in prioritising topics to be taken further by PenCLAHRC as the basis for a specific evaluation or implementation research project. This paper was compiled in 2-3 days. The briefing is in four parts:

- General context
- The question in a structured format
- What the research evidence says
- Alignment with PenCLAHRC research priority criteria

QUESTION: How can we best design, evaluate and implement a group-based programme for weight-management in tier 3 obesity care?

General context and definitions: Tier 3 obesity care is for obese individuals (usually with a body mass index ≥35 with comorbidities or 40+ with or without co-morbidities) who have not responded to previous tier 1 or 2 interventions. A tier 3 service is comprised of a multi-disciplinary team of specialists, led by a clinician and typically including, amongst others: a physician (consultant or GP with a special interest); specialist nurse; specialist dietitian; psychologist or psychiatrist; and physiotherapist/physical activity specialist/physiology. There is widespread variability in availability of tier 3 services for weight management throughout the UK.

Obesity is a major challenge for health services worldwide. Obesity is associated with an increased risk for cardiovascular disease, type 2 diabetes, hypertension, dyslipidaemia, and other diseases. The percentage of patients with extreme and complex obesity is increasing. Clinical obesity management guidelines recommend a multidisciplinary approach that includes behavioural intervention. While intense behavioural interventions have been delivered successfully by several clinical trials these interventions have not translated into usual care for a variety of reasons including lack of suitable expertise and insufficient resources.

Commercial weight loss programmes and trial-based research have shown that group therapy is more successful for maintenance of weight loss than one-to-one programmes. With increasing demand for obesity care, increasing demands on resources, and potential benefits of increased motivation and adherence through group therapy, might there be benefit in providing group-based tier 3 care?

The question in a structured format: In considering this as a research question, we could frame it as following:

Population:	People with a body mass index ≥35 with comorbidities or 40+ with or without co-morbidities
Intervention:	Multi-disciplinary weight management tier 3 care, delivered in a group format (exploring different group formats/composition)
Comparator:	Usual care (could be either individual weight management tier 3 care or waiting list)
Outcomes of Interest:	Patient experience, health outcomes (including weight loss), program adherence, long-term benefits

What the research evidence says: Whilst there are an extensive number of systematic reviews on the effectiveness of commercial weight management programs and research-based lifestyle interventions, there are no systematic reviews of tier 3 obesity care in practice. A few studies of tier 3 service evaluations have recently been published in the peer-reviewed literature. Brown and colleagues[1] report early findings from a group-based intervention to help treat morbid obesity, as well obesity with comorbidities, within a specialist weight management service based at the Heart of England NHS Foundation Trust in Birmingham. The Specialist Lifestyle Management (SLiM) is a structured patient education and self-management group weight management programme. Six month results suggest the SLiM model has helped patients achieve a clinically significant weight loss and an improvement in diabetes control. The programme provides care to patients within a specialist service over a 24-week period. Jennings and colleagues[2] report on an evaluation of a multidisciplinary tier 3 weight management service for adults with morbid obesity, or obesity and comorbidities, based in primary care in Norfolk. The format of the service was on a one-to-one basis, and resulted in a progressive and substantial reduction in weight at one year, with weight losses achieved of 5% or more of initial weight. Whilst both evaluations above were effective in the short term (6-12months), the authors recognised that the challenge is for the weight loss to be maintained in the long term. There is a need for longer-term follow-up data, as well as further assessment of predictors of attrition to allow the studies to have greater generalisability. Whether group-based services would be more effective than services delivered on a one-to-one basis needs to be explored.

The Royal College of Surgeons commissioning guide[3] for tier 3 weight management and treatment identified a severe lack of evidence on the outcomes from ‘weight assessment and management’ services. An increasing number of services are being commissioned, but as yet few have published outcome data. They concluded that more research is required to define the most effective composition of the team, and what are realistic clinical outcomes. Improvement in both physical and psychological health rather than weight loss alone needs to be studied and reported on.

With such little primary research data on tier 3 obesity care currently available, there is little evidence to help inform the ideal format of tier 3 care, i.e. whether group therapy is better than one-to-one treatment, or how best to organise group therapy with regards to team composition and intervention dose, frequency or length of follow-up. However, existing evidence from lifestyle interventions studies and commercial weight management trials shows that group-based weight management programmes are more successful than one-to-one programmes, even in patients who initially indicate a preference for individual care [4-6].

Ongoing studies/ Trials in progress: No ongoing research trials of group based tier 3 services for obesity care were located in the peer-reviewed literature. In the grey literature, we found several reports of group-based tier 3 obesity services being offered in various parts of the UK, though whether these are being assessed for feasibility or effectiveness is not reported.

How does this fit with PenCLAHRC research priority criteria?

Size of the health problem: Overweight and obesity are global problems and the World Health Organization predicts that by 2015 approximately 2.3 billion adults worldwide will be overweight and more than 700 million obese. In the UK, obesity rates have nearly doubled in the past 18 years from 13% of men and 16% of women in 1993, to 24% of men and 26% of women in 2011[7]. Obesity is directly linked to a number of different illnesses including type 2 diabetes, hypertension, gallstones and gastro-oesophageal reflux disease, as well as psychological and psychiatric morbidities. The Health and Social Care Information Centre reported that there were 11,740 inpatient admissions to hospitals in England with a primary diagnosis of obesity in 2011/2012, which is 3 times as many as 5 years earlier in 2006/2007. The cost of overweight and obesity to society and the economy was estimated to be almost £16 billion in 2007 (over 1% of gross domestic product). The cost could increase to just under £50 billion in 2050 if obesity rates continue to rise, according to projections from the Department of Health. A simulated model reported in the Lancet predicted that there would be 11 million more obese adults in the UK by 2030, with combined medical costs for treatment of associated diseases estimated to increase by £1.9–2 billion/year[7].

The potential for health improvement: Weight loss in overweight and obese individuals improves physical, psychological and social health. There is good evidence to suggest that a moderate weight loss of 5-10% of body weight in obese individuals is associated with significant health benefits, particularly a reduction in blood pressure and a reduced risk of developing type 2 diabetes or coronary heart disease. A 10kg weight loss has been projected to result in more a 20% reduction in total mortality, more than a 30% reduction in diabetes-related deaths, and more than a 40% reduction in obesity-related cancer deaths[8]. Both evaluations of the tier 3 obesity services reported on the previous page reported weight losses in the region of 5-10kg over 6 to 12 months.

The practicality of the research question: There is variability in access to tier 3 weight management services across the country. From the few examples found in the grey literature, there is also variability in the format of the tier 3 service provided, but at present few published reports about feasibility or effectiveness. The local weight management service in Plymouth – see below- (and possibly others around the SW), may be interested in primary research assessing the impact of the tier 3 service group composition along with other intervention characteristics on weight loss maintenance.

Whether the South West is a good place to do this research: According to latest data from the Health Survey for England[9], 23% of women in the South West are obese and 24% for men are obese, which compares to 24% and 26% respectively nationally.

Locally, the Plymouth weight management clinic (WMC) was commissioned in 2006. The service is community-based in the deprived area of Devonport which has high levels of obesity-related health problems. Due to the large numbers of patients being referred, in order to provide sufficient contact time and frequency, Plymouth WMC already adopts a group approach intervention. For the Plymouth WMC, the most important single question for the clinic is how can patient groups be used most effectively in the WMC context? Dr Mark Tarrant and colleagues at the University of Exeter have expertise in group therapy for health behaviour change and have expressed interest in investigating the dynamics of group therapy for tier 3 care.

Alignment with local health priorities: This will be different across the South West region and between organisations. Please consider the briefing in line with your local priorities.

GUIDELINES & GOVERNMENT STRATEGIES relating to this area:

NHS England (2014). Joined up Clinical Pathways for Obesity: Report of the Working Group. NHS England, London. Available at: https://www.england.nhs.uk/wp-content/uploads/2014/03/owg-join-clinc-path.pdf

This report examines the issues that have arisen in the provision and access to, the integrated obesity care pathway for adults and children. In particular it examines access to more intensive, targeted and multidisciplinary approaches to weight management.

National Institute of Health and Care Excellence (2014). Obesity: Identification, assessment and management of overweight and obesity in children, young people and adults. NICE Guidelines CG189. [Online]. 2014. Available from: http://www.nice.org.uk/guidance/cg189

This guideline updates and replaces section 1.2 of NICE guideline CG43 (published December 2006). It offers evidence-based advice on the care and treatment of Obesity.

Royal College of Surgeons (2014). Commissioning Guide: Weight assessment and management clinics (tier 3). Available from: https://www.rcseng.ac.uk/healthcare-bodies/docs/weight-assessment-and-management-tier-3-services.

This guidance examines the role of the referring GP, what should be achieved in the weight assessment clinics and who should be referred for bariatric surgery. With the lack of consistency in the provision of medical obesity services, this guidance provides an organised structure and evidence-base for treatment, guidance for referral into and out of the tier 3 service: either back to primary care (Tier 2) or onto specialist or surgical assessment (Tier 4).

Relevant Abstracts:

Brown A, et al. Description and preliminary results from a structured specialist behavioural weight management group intervention: Specialist Lifestyle Management (SLiM) programme. BMJ Open. 2015 Apr 8;5(4)

Background: Specialist Lifestyle Management (SLiM) is a structured patient education and self-management group weight management programme. Each session is run monthly over a 6-month period providing a less intensive long-term approach. The groups are patient-centred incorporating educational, motivational, behavioural and cognitive elements. The theoretical background, programme structure and preliminary results of SLiM are presented.

Subjects/methods: The study was a pragmatic service evaluation of obese patients with a body mass index (BMI) ≥35 kg/m2 with comorbidity or ≥40 kg/m2 without comorbidity referred to a specialist weight management service in the West Midlands, UK. 828 patients were enrolled within SLiM over a 48-month period. Trained facilitators delivered the programme. Preliminary anonymised data were analysed using the intention-to-treat principle. The primary outcome measure was weight loss at 3 and 6 months with comparisons between completers and non-completers performed. The last observation carried forward was used for missing data.

Results: Of the 828 enrolled within SLiM, 464 completed the programme (56%). The mean baseline weight was 135 kg (BMI=49.1 kg/m2) with 87.2% of patients having a BMI≥40 kg/m2and 12.4% with BMI≥60 kg/m2. The mean weight change of all patients enrolled was −4.1 kg (95% CI −3.6 to −4.6 kg, p=0.0001) at the end of SLiM, with completers (n=464) achieving −5.5 kg (95% CI −4.2 to −6.2 kg, p=0.0001) and non-completers achieving −2.3 kg (p=0.0001). The majority (78.6%) who attended the 6-month programme achieved weight loss with 32.3% achieving a ≥5% weight loss.

Conclusions: The SLiM programme is an effective group intervention for the management of severe and complex obesity.

Jennings A, et al. Tier 3 weight management service for adults with morbid obesity, or obesity and comorbidities, based in primary care. Clinical Obesity 2014 4(5): 254-266.

Summary

A multidisciplinary Tier 3 weight management service in primary care recruited patients with a body mass index ≥40 kg·m−2, or 30 kg·m−2 with obesity-related co-morbidity to a 1-year programme. A cohort of 230 participants was recruited and evaluated using the National Obesity Observatory Standard Evaluation Framework. The primary outcome was weight loss of at least 5% of baseline weight at 12 months. Diet was assessed using the two-item food frequency questionnaire, activity using the General Practice Physical Activity questionnaire and quality of life using the EuroQol-5D-5L questionnaire. A focus group explored the participants' experiences. Baseline mean weight was 124.4 kg and mean body mass index was 44.1 kg·m−2. A total of 102 participants achieved 5% weight loss at 12 months. The mean weight loss was 10.2 kg among the 117 participants who completed the 12-month programme. Baseline observation carried forward analysis gave a mean weight loss of 5.9 kg at 12 months. Fruit and vegetable intake, activity level and quality of life all improved. The dropout rate was 14.3% at 6 months and 45.1% at 1 year. Focus group participants described high levels of satisfaction. It was possible to deliver a Tier 3 weight management service for obese patients with complex co-morbidity in a primary care setting with a full multidisciplinary team, which obtained good health outcomes compared with existing services.

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PRIORITY BRIEFING ID 49

The purpose of this briefing paper is to aid Stakeholders in prioritising topics to be taken further by PenCLAHRC as the basis for a specific evaluation or implementation research project. This paper was compiled in 2-3 days. The briefing is in four parts:

- General context
- The question in a structured format
- What the research evidence says
- Alignment with PenCLAHRC research priority criteria

QUESTION: Does having a seven day community-based intermediate care service improve patient and service outcomes, as well as demonstrate value for money?

General context and definitions: There has been an expansion of services for intermediate care in the UK. Such services are usually targeted at older people after leaving hospital or when they are at risk of being sent to hospital. They aim to prevent 'avoidable' admissions to acute inpatient care; facilitate the timely discharge of patients from acute inpatient care; promote patient independence and rehabilitation. A range of services might fall under the banner of intermediate care e.g. crisis response, home-based care, bed-based care (a bed within an acute hospital, community hospital, residential care home, nursing home, standalone intermediate care facility, independent sector facility, Local Authority facility or other bed based setting), and reablement. They are usually delivered in patients' homes or in non-acute institutions e.g. community hospitals or residential homes. There is a call for intermediate care services to be able to provide care seven days a week, which is believed may reduce emergency hospital admissions particularly at the weekend when there is currently no other service provision.

The question stems from interest in the organisation of intermediate care services in Torbay and South Devon. Throughout the Torbay and South Devon region there have been different developments in different localities, resulting in varying professionals delivering services or varying availability (five day versus seven day access). Consequently, there is inconsistency within the region which may impact on patient outcomes. However, there is currently no guidance available on offering five or seven days intermediate care services and the consequences of adopting one service configuration or another are not clear.

The question in a structured format: In considering this as a research question, we could frame it as:

Population:	Adults aged 18 and over referred to Torbay and South Devon Health Care Trust Intermediate care service
Intervention:	Seven day community-based intermediate care provision
Comparator:	Five day community-based intermediate care provision
Outcomes of Interest:	Patient outcomes (functional ability, patient experience, goal achievement) Service outcomes (admissions – hospital or care home, length of stay, duration on caseload) and Costs

What the research evidence says: No research was located that compared the provision of intermediate care services over seven days with any other pattern.

The *National Audit of Intermediate Care 2015*[1] states that seven day services are essential if intermediate care is to make an impact on admission avoidance. The audit found that most intermediate care services are open to new admissions 365 days a year (although home-based and reablement services are less likely to be). Of these services, most offer extended hours of access (although this is again lower for home based and reablement services) and very few services offer true 24/7 access to care. However, waiting times for access to these services have increased over the last three years with average waiting times currently standing at 3.7 hours for crisis response, 1.3 days for bed based, 6.3 days for home based and 8.7 days for reablement services. This suggests that intermediate care services are struggling to meet demand and therefore may be less able to reduce pressure on secondary care and social care services. Services that do not offer a seven day service limit their ability to reduce unavoidable admissions to acute care by providing no alternative care services over the weekend[1].

The audit[1] reports that intermediate care based at home costs approximately £1205 per service user, crisis response £521, reablement £1484 and bed based costs £5672. For this investment on average 92% of patients improve or maintain their levels of dependence irrespective of the form of delivery (home based, bed based or reablement) they receive.

Ongoing studies/ Trials in progress: Some mapping work on Rapid (Crisis) Response services (which is one aspect of intermediate care services) available in Devon and Cornwall is being conducted as a result of a question raised in the last round of PenCLAHRC prioritisation. This work is currently waiting to receive data regarding services in various locations; contacting the appropriate people to obtain this information has been challenging. There have also been difficulties in identifying the relevant services that fall under the ‘Rapid Response’ description as not all such services are labelled this way or with other intermediate care-related labels. Emerging findings from this work suggest that Rapid Response services are not always provided (e.g. Cornwall does not provide ‘Crisis Response’ services and focuses mainly on supporting discharge from hospital) and those that are provided are not uniform in how they look or how they work. Lessons could be learned from this work to inform development of the current question.

There are a number of new intermediate care-type services being set up in Exeter (Integrated Care Exeter – focusing on avoiding hospital admissions and facilitating discharge) and Somerset (South Somerset Symphony Initiative – focusing on avoiding hospital admissions) and these are going to be evaluated by PenCLAHRC on behalf of the AHSN. There was until recently a Frailty Hub in Newton

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[1] Please note organisations had to pay a fee to have their data included in this audit and participation was voluntary (no organisations in Devon and Cornwall participated) consequently the results may over-estimate the level of seven day services and beyond 9-5 extended services provided nationwide. The report is based on data from services in England only (none submitted from Scotland or Wales). Data was provided by 340 services registered by 95 providers (48 crisis response, 109 home based intermediate care services, 139 bed based intermediate care services and 44 re-ablement services). 83% of commissioners who submitted in 2014 also submitted in 2015.

Abbot which also provided assessment and care to reduce avoidable hospital admissions. In Cornwall there is the Living Well initiative as a version of intermediate care also focusing on reducing avoidable hospital admissions. It is unclear if any of these services are provided seven days a week. Contact with these services and others may help with any development of this question.

How does this fit with PenCLAHRC research priority criteria?

Size of the health problem: Emergency admissions (admissions that are not predicted and happen at short notice because of perceived clinical need) are rising, with 5.4 million emergency admissions recorded in 2013/14, an increase of 1.5 per cent from the previous year[2]. There were 162,103 emergency admissions in Devon and Cornwall in 2013/14 (161,689 in 2012/13). In 2012 each emergency admission in Devon was purported to cost approximately £1883[3]. Ambulatory care sensitive (ACS) conditions are chronic conditions for which it is possible to prevent acute exacerbations and reduce the need for hospital admission through active management or lifestyle interventions e.g. congestive heart failure, diabetes, asthma, angina, epilepsy and hypertension [4]. ACS conditions account for 16 per cent of all emergency hospital admissions in England and thirty percent of these are individuals > 75 years of age[5]. ACS conditions cost the NHS £1.42 billion annually[5]. Seven day access to services to help treat or prevent exacerbations may help to avoid/reduce hospital admissions.

The potential for health improvement: Nationally people admitted over the weekend have a greater risk of dying within 30 days of admission than those admitted on a week day (in some places the mortality is increased by 16%)[6]. Longer hospital stays increase the risk of acquiring hospital based infections and increase the degree of lost mobility due to increased time in bed and this is exacerbated at the weekend due to the lack of community-based resources, senior clinical review and timely access to appropriate therapies[6].

The *NHS Services, Seven Days a Week Forum: Summary of Initial Findings* 2013 reports that teams that have made changes towards provision of seven day services, achieved benefits for patients including: the speed of assessment diagnosis and treatment; intervention to spot and prevent deterioration; safer and more timely supported discharge; and reduced risk of emergency readmission. These teams also found that there were organisational benefits to moving toward provision of seven day services, such as: avoidance of waste and repetition; fewer complications; admission to the right place, first time; better supervision of the work of doctors in training; more efficient use of expensive plant and equipment; shorter length of stay; and reduced bed pressure Monday to Friday.

The practicality of the research question: Learning from the ongoing work on Rapid/Crisis Response services in the South West will be important. Operational research modelling may be an option to explore this question, though will be reliant on appropriate data. The intermediate care audit may assist in this regard although there are many limitations with the audit and the applicability of that data to the South West. Intermediate care services have a broad range of design and implementation. Establishing a meaningful definition with which to guide future primary research studies looking at the effectiveness of five vs. seven day services would be a necessary step.

Whether the South West is a good place to do this research: The South West Peninsula has an older population than the England average. According to the Projecting Older People Population Information System, by the Institute for Public Care and Oxford Brooks University (www.poppi.org.uk), in 2014 there are over 1.14 million people aged over 65 living in the South West, of which 165, 000 are aged over 85. By 2025 there is forecast to be a 25 per cent rise in people aged over 65, and a 50 per cent rise in those aged over 90. A 2009 HSMC Health Services Management Centre paper indicates that Torbay has piloted weekend services[7] though no data can be found for this.

Alignment with local health priorities: This will be different across the South West region and between organisations. Please consider the briefing in line with your local priorities.

GUIDELINES & GOVERNMENT STRATEGIES relating to this area:

NHS Services, Seven Days a Week Forum: Summary of Initial Findings 2013, highlights the need for seven day services and issues with their implementation. The report also highlights potentially useful budgets for service changes as follows: ‘In 2014/15 £1.1 billion is being made available to Local Authorities to support health and social care services to work more closely together in local areas. By 2015/16 the Better Care Fund (BCF) will be a single pooled budget of £3.8 billion.’

NHS Services open seven days a week: Every day counts 2013, offers tips on how to implement seven day services, and case studies and examples of how hospitals, community health and social care services across the country are working together to deliver routine services seven days a week.

National Audit of Intermediate Care Summary Report 2015 Assessing progress in services for older people aimed at maximising independence and reducing use of hospitals also highlights the need for seven day services and the current variability in provision. This report also discusses patient experience with the service and the importance of multidisciplinary team formulation.

Improving the quality and safety of urgent and emergency care, including reducing unplanned admissions, is outlined as a priority in the NHS Commissioning Report *Everyone Counts: Planning for Patients 2013/14*[8].

The NHS England ‘*Urgent and emergency care review’* from 2013[9] concluded that there is a clear need to adopt a whole-system approach to commissioning more accessible, integrated and consistent urgent and emergency care services to meet patients unscheduled care needs

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PRIORITY BRIEFING ID 50

The purpose of this briefing paper is to aid Stakeholders in prioritising topics to be taken further by PenCLAHRC as the basis for a specific evaluation or implementation research project. This paper was compiled in 2-3 days. The briefing is in four parts:

- General context
- The question in a structured format
- What the research evidence says
- Alignment with PenCLAHRC research priority criteria

QUESTION: How should team composition and team working be optimised for delivering three different intermediate care functions (reducing avoidable admissions, facilitating discharge and supporting community rather than hospital care) and generating improved patients and service outcomes as well as cost?

General context and definitions: There has been an expansion of services for intermediate care in the UK. Such services are usually used by older people after leaving hospital or when they are at risk of being admitted to hospital. They aim to prevent 'avoidable' admissions to acute inpatient care; facilitate the timely discharge of patients from acute inpatient care; promote independence and provide rehabilitation. A variety of different professionals can deliver this type of specialised care, from nurses and therapists to social workers. The person or team providing the care plan will depend on the care user’s needs. Many intermediate care services operate at the interface of numerous agencies, settings and professional groups, and require workforce structures that can reflect and respond to this complexity. There is a lack of research about the 'best way' to staff an intermediate care service although results from the *National Audit of Intermediate Care*[1] may be helpful.

The question stems from interest in the organisation of intermediate care services in Torbay and South Devon. Throughout the organisation there have been different developments in different localities resulting in different professionals delivering these services. For example, in Torquay, the core team include physiotherapists, occupational therapists, nurses, social workers, mental health workers, a pharmacist and a GP, as well as support workers. However, in South Devon, the core team are physiotherapists and occupational therapists. Thus, there is inconsistency across the region which may impact on patient outcomes.

The question in a structured format: In considering this as a research question, we could frame it as following:

Population:	Adults aged 18 and over referred to Torbay and South Devon Health Care Trust Intermediate care service
Intervention:	Services provided by multidisciplinary core team physiotherapists, occupational therapists, nurses, social workers, mental health workers, pharmacists and GPs
Comparator:	Services provided by a basic core team of physiotherapists and occupational therapists who access other professionals on an as-needed basis
Outcomes of Interest:	Patient outcomes (functional ability, patient experience, goal achievement); Service outcomes (admissions – hospital or care home, length of stay, duration on caseload); Costs

What the research evidence says: A recent review[2] examined the effectiveness of different models of intermediate care on a range of patient outcomes. The results of the review suggested that intermediate care was more effective (assessed in a number of ways) among teams that have a higher skill mix (i.e. larger number of different disciplines), with effectiveness improving with each additional discipline represented in the team. However, as the results are based on just five studies the results should be interpreted with caution. The review recommended that more high-quality studies that aim to examine what specific team-level factors are associated with better outcomes for patients are needed. Another review looked at the cost effectiveness of different models of care but only used data from two studies. Costs per patient showed great variation and cost-effectiveness was highly variable, with the size of service being the only reported explanation of effect. There is little evidence of a commonly agreed vision and purpose for intermediate care services and there is a tension between the specialisation and hierarchy seen in other areas of the NHS and the more generalised and collaborative approaches needed in multidisciplinary intermediate care teams.

The *National Audit of Intermediate Care*[1] reports some variability in the number of staff needed to provide different types of intermediate care, and also variability in the staff mix for each service. For example, registered nurses and health care support workers make up the majority of the staff mix within crisis response, home and bed based care services; whilst social care support workers making up the majority of the staff mix in reablement services. Allied health professional, social workers, other medical staff (not in reablement) and support staff make up the remainder of the mix. In the NAIC[1] commissioners were asked if any transdisciplinary roles had developed over the past year, and the response was that 31% of integrated home and reablement services and 43% of integrated home and bed based services had developed such a role. However, the most common model of clinical leadership within intermediate care services were nurses (in 67% of crisis response and 50% of bed based services), therapists (in 51% of home based services) and social care/ case managers (53% of reablement services). Commissioners also reported that about half the intermediate care services have staff working across health and social care but that only a quarter of these services have joint training and induction programmes suggesting there is room to integrate the services more fully. The presence of mental health professionals/services within intermediate care was limited with commissioners reporting mental health specialist roles approximately a quarter of integrated home and bed based and home and reablement based services.

Ongoing studies/ Trials in progress: Some mapping work on Rapid (Crisis) Response services (which is one aspect of intermediate care services available) in Devon and Cornwall is being conducted as a result of a question raised in the 2014 prioritisation. This work is currently waiting for data regarding these services to come in from various locations. Contacting the appropriate people to obtain this information has been challenging. Emerging findings from this work suggest that Rapid Response services are not always provided (e.g. Cornwall does not provide 'Crisis Response' services and focuses mainly on supporting discharge from hospital) and those that are provided are not uniform in how they look or how they work. Lessons could be learned from this work to inform development of the current question.

The University of Oxford is conducting a multi-centre randomised controlled trial of Comprehensive Geriatric Assessment in an admission avoidance hospital at home setting. This study will look at health outcomes such as death, living at home, transfer to hospital and admission to residential care, the patient and carer experience as well as the cost effectiveness of two service models - the provision of admission avoidance hospital at home setting with specialist led geriatric care vs. specialist hospital care for the frailer older adult. This is due to be published in 2019.

There are a number of new intermediate care-type services being set up in Exeter (Integrated Care Exeter – focusing on avoiding hospital admissions and facilitating discharge) and Somerset (South Somerset Symphony Initiative – focusing on avoiding hospital admissions) which are going to be evaluated by PenCLAHRC on behalf of the AHSN. There was until recently a Frailty Hub in Newton Abbott which also provided assessment and care to reduce avoidable hospital admissions. In Cornwall there is the Living Well initiative as a version of intermediate care also focusing on reducing avoidable hospital admissions. All of these services aim to provide a form of multidisciplinary care with patients usually having an assessment followed by the appropriate care services need for that individual. In services that are also facilitating hospital discharge, patients will have a key worker to monitor the discharge process and ensure they are given the appropriate reablement service/package of services. The details of the skill mix to be used in providing these services is unclear at present, but is expected to be varied with each service. Contact with these services and others may help with development of this question.

How does this fit with PenCLAHRC research priority criteria?

Size of the health problem: Emergency admissions (admissions that are not predicted and happen at short notice because of perceived clinical need) are rising, with 5.4 million emergency admissions recorded in 2013/14, an increase of 1.5 per cent from the previous year[3]. There were 162,103 emergency admissions in Devon and Cornwall in 2013/14 (161,689 in 2012/13). In 2012 each emergency admission in Devon was purported to cost approximately £1883[4]. Ambulatory care sensitive (ACS) conditions are chronic conditions for which it is possible to prevent acute exacerbations and reduce the need for hospital admission through active management or lifestyle interventions e.g. congestive heart failure, diabetes, asthma, angina, epilepsy and hypertension[5]. ACS conditions account for 16 per cent of all emergency hospital admissions in England and thirty percent of these are individuals > 75 years of age[6]. ACS conditions cost the NHS £1.42 billion annually[6]. Providing the right care (staff skill mix), at the right time, may help to prevent people with ACS conditions needing to receive urgent hospital care.

The potential for health improvement: Longer hospital stays increase the risk of acquiring hospital based infections and increase the degree of lost mobility due to increased time in bed[7] . Access to the appropriate intermediate care staff or service to facilitate hospital discharge could result in reduced time in hospital and increased likelihood of maintaining independence in their everyday lives.

The Torquay model is more costly in terms of staffing but it is unclear as to whether it results in better patient and service outcomes than the South Devon model, and thus better value for money in the longer term. The NAIC does not make any recommendations for the appropriate skill mix that should be available in intermediate care services as it highlights that one size (combination of skills) will not fit all with each individual service user (as well as service area) having differing needs. However, the audit does seem to support the development of trans-disciplinary roles (staff working across health and social care) and the need to provide appropriate joint training and induction programmes. One concern that has been highlighted is that if the rapid response service is delivered by the same staff who also provide general preventative rehabilitation, those who are referred for rehabilitation may experience delays in receiving their service as those with urgent needs will be dealt with first. This may lead to such delays in service that those who were initially referred to rehabilitation result in needing urgent care due to the delay in their rehabilitation service. This highlights the need to have enough staff with the appropriate skills to ensure the team configuration can avoid these pitfalls and provide the right care at the right time. Access to the right care at the right time will work both to avoid hospital admissions and support hospital discharge and having a variety professionals on the intermediate care team may help to achieve that rather than care having to be delayed whilst the service user is redirected to different service providers.

The practicality of the research question: Learning from the ongoing work on Rapid/Crisis Response services in the South West will be important. Intermediate Care services have a range of team configurations. Establishing this detail within the region to inform a primary research study looking at the effectiveness of team configurations on agreed outcomes would be an important first step.

Whether the South West is a good place to do this research: The South West Peninsula has an older population than the England average and therefore a greater proportion of intermediate care services will be needed to meet their care needs. According to the Projecting Older People Population Information System, by the Institute for Public Care and Oxford Brooks University (www.poppi.org.uk), in 2014 there are over 1.14 million people aged over 65 living in the South West, of which 165, 000 are aged over 85, a third of which are aged over 90. By 2025 there is forecast to be a 25 per cent rise in people aged over 65, and a 50 per cent rise in those aged over 90. Torbay also has experience of integrated and coordinated working.

Alignment with local health priorities: This will be different across the South West region and between organisations. Please consider the briefing in line with your local priorities.

GUIDELINES & GOVERNMENT STRATEGIES relating to this area:

National Audit of Intermediate Care Summary Report 2015 Assessing progress in services for older people aimed at maximising independence and reducing use of hospitals highlights the need for seven day services and the current variability in provision. This report also discusses patient experience with the service and the importance of multidisciplinary team formulation.

Improving the quality and safety of urgent and emergency care, including reducing unplanned admissions, is outlined as a priority in the NHS Commissioning Report *Everyone Counts: Planning for Patients 2013/14*[8].

The NHS England '*Urgent and emergency care review'* from 2013[9] concluded that there is a clear need to adopt a whole-system approach to commissioning more accessible, integrated and consistent urgent and emergency care services to meet patients unscheduled care needs .

Relevant Abstracts:

Ariss SM, Enderby PM, Smith T, Nancarrow SA, Bradburn MJ, Harrop D, et al. Secondary analysis and literature review of community rehabilitation and intermediate care: an information resource. Health Serv Deliv Res 2015;3(1).

Background and design: This research was based on a reanalysis of a merged data set from two intermediate care (IC) projects in order to identify patient characteristics associated with outcomes Additionally, the impact of different team and staffing structures on patient outcomes and service costs was examined, when possible given the data sets, to enable identification of the most cost-effective service configurations and change over time with service provision. This secondary analysis was placed within updated literature reviews focused on the separate questions.
Research objectives: (1) To identify those patients most likely to benefit from IC and those who would be best placed to receive care elsewhere; (2) to examine the effectiveness of different models of IC; (3) to explore the differences between IC service configurations and how they have changed over time; and (4) to use the findings above to develop accessible evidence to guide service commissioning and monitoring.
Setting: Community-based services for older people are described in many different ways, among which are IC services and community rehabilitation. For the purposes of this report we call the services IC services and include all community-based provision for supporting older people who would otherwise be admitted to hospital or who would require increased length of stay in hospital (e.g. hospital at home schemes, post-acute care, step-up and step-down services).
Participants & Interventions: The combined data set contained data on 8070 patient admissions from 32 IC teams across England and included details of the service context, costs, staffing/skill mix (800 staff), patient health status and outcomes. The interventions associated with the study cover the range of services and therapies available in IC settings. These are provided by a wide range of professionals and care staff, including nursing, allied health and social care.
Outcome measures: (1) Service data ‐ each team provided information relating to the size, nature, staffing and resourcing of the services. Data were collected on a service pro forma. (2) Team data ‐ all staff members of the teams participating in both studies provided individual information using the Workforce Dynamics Questionnaire. (3) Patient data ‐ patient data were collected on admission and discharge using a client record pack. The client record pack recorded a range of data utilising a number of validated tools, such as demographic data, level of care (LoC) data, therapy outcome measure (TOM) scale, European Quality of Life-5 Dimensions (EQ-5D) questionnaire and patient satisfaction survey.
Results: (1) The provision of IC across England is highly variable with different referral routes, team structures, skill mix and cost-effectiveness; (2) in more recent years, patients referred to IC have more complex needs associated with more severe impairments; (3) patients most likely to improve were those requiring rehabilitation as determined by levels 3, 4 and 5 on the LoC (> 40% for impairment, activity and participation, and > 30% for well-being as determined on the TOM scale); (4) half of all patients with outcome data improved on at least one of the domains of the TOM scale; (5) for every 10-year increase in age there was a 6% decrease in the odds of returning home. The chance of remaining or returning home was greater for females than males; (6) a high percentage of patients referred to IC do not require the service; and (7) teams including clinical support staff and domiciliary staff were associated with a small relative improvement in TOM impairment scores when compared with other teams.

Conclusions: This study provides additional evidence that interdisciplinary teamworking in IC may be associated with better outcomes for patients, but care should be taken with overinterpretation. The measures that were used within the studies were found to be reliable, valid and practical and could be used for benchmarking. This study highlights the need for funding high-quality studies that attempt to examine what specific team-level factors are associated with better outcomes for patients. It is therefore important that studies in the future attempt empirically to examine what process-level team variables are associated with these outcomes.

Studies from the Ariss review:

Regen E, Martin G, Glasby J, Hewitt G, Nancarrow S, Parker H. Challenges, benefits and weaknesses of intermediate care: results from five UK case study sites. Health Soc Care Community 2008;16:629–37.

The authors explore the views of practitioners and managers on the implementation of intermediate care for elderly people across England, including their perceptions of the challenges involved in its implementation, and their assessment of the main benefits and weaknesses of provision. Qualitative data were collected in five case study sites (English primary care trusts) via semistructured interviews ($n = 61$) and focus group discussions ($n = 21$) during 2003 to 2004. Interviewees included senior managers, intermediate care service managers, clinicians and health and social care staff involved in the delivery of intermediate care. The data were analysed thematically using an approach based on the 'framework' method. Workforce and funding shortages, poor joint working between health and social care agencies and lack of support/involvement on the part of the medical profession were identified as the main challenges to developing intermediate care. The perceived benefits of intermediate care for service-users included flexibility, patient centredness and the promotion of independence. The 'home-like' environment in which services were delivered was contrasted favourably with hospitals. Multidisciplinary teamworking and opportunities for role flexibility were identified as key benefits by staff. Insufficient capacity, problems of access and awareness at the interface between intermediate care and 'mainstream' services combined with poor co-ordination between intermediate care services emerged as the main weaknesses in current provision. Despite reported benefits for service-users and staff, the study indicates that intermediate care does not appear to be achieving its full potential for alleviating pressure within health and social care systems. The strengthening of capacity and workforce, improvements to whole systems working and the promotion of intermediate care among doctors and other referrers were identified as key future priorities.

Blewett LA, Johnson K, McCarthy T, Lackner T, Brandt B. Improving geriatric transitional care through inter-professional care teams. J Eval Clin Prac 2010;16:57–63.

Objectives: The aim of this study was to examine the impact of the use of an inter-professional care team on patient length of stay and payer charges in a geriatric transitional care unit. Methods: An analysis of de-identified administrative records for transitional care patients for the 12-month period (2003–2004) cared for by the inter-professional team (n = 163) and cared for by traditional single provider care model (n = 176) was carried out. We conducted logistic regression on length of stay and charges controlling for patient demographics and acuity levels. Results: The inter-professional care team patients had significantly shorter lengths of stay, fewer patient days and lower total charges. Patient diagnosis and acuity were similar across groups. Conclusion: This study provides empirical evidence of the impact of an inter-professional care model in providing cost-effective transitional care in a nursing home setting. Evidence of shorter lengths of stay, shorter patient days and lower charges suggests benefit in the development and financing of inter-professional care teams for transitional care services.

Dixon S, Kaambwa B, Nancarrow S, Martin GP, Bryan S. The relationship between staff skill mix, costs and outcomes in intermediate care services. BMC Health Serv Res 2010;10:221.

Background: The purpose of this study was to assess the relationship between skill mix, patient outcomes, length of stay and service costs in older peoples' intermediate care services in England. Methods: We undertook multivariate analysis of data collected as part of the National Evaluation of Intermediate Care Services. Data were analysed on between 337 and 403 older people admitted to 14 different intermediate care teams. Independent variables were the numbers of different types of staff within a team and the ratio of support staff to professionally qualified staff within teams. Outcome measures include the Barthel index, EQ-5D, length of service provision and costs of care. Results: Increased skill mix (raising the number of different types of staff by one) is associated with a 17% reduction in service costs (p = 0.011). There is weak evidence (p = 0.090) that a higher ratio of support staff to qualified staff leads to greater improvements in EQ-5D scores of patients. Conclusions: This study provides limited evidence on the relationship between multidisciplinary skill mix and outcomes in intermediate care services.

Bird S, Noronha M, Sinnott H. An integrated care facilitation model improves quality of life and reduces use of hospital resources by patients with chronic obstructive pulmonary disease and chronic heart failure. Aust J Prim Health 2010;16:326–33.

As part of the Department of Human Services Hospital Admissions Risk Program (HARP), a group of acute and community based health care providers located in the western suburbs of Melbourne formed a consortium to reduce the demand on hospital emergency services and improve health outcomes for patients with chronic obstructive pulmonary disease (COPD) and chronic heart failure (CHF). The model of care was designed by a team of multidisciplinary specialists and medical consultants. In addition to receiving normal care, patients recruited to the project were assessed by ‘Care Facilitators’, who identified unmet health care needs and provided information, advice and education for the patient concerning their condition and self-management. Patients declining recruitment received all normal care services. The patients’ rates of emergency department (ED) presentations, inpatient admissions and hospital inpatient bed-days before and after their recruitment were calculated from the Western Health patient activity records, and pre- versus post-recruitment rates were compared using ANOVA. Changes relative to the ongoing use by those who declined recruitment were compared using the group-by-time interaction. Patient health outcomes were assessed using established disease-specific tools, and pre- versus post-recruitment values were compared using paired t-tests. Patients recruited to the COPD project reduced ($P < 0.05$) their emergency presentations, admissions and hospital inpatient bed-days by 10, 25 and 18%, respectively, whereas those declining recruitment increased their usage by 45, 41 and 51% respectively. Recruited CHF patients also displayed reductions in emergency presentations (39%), admissions (36%) and hospital inpatient bed-days (33%), whereas those who declined recruitment displayed lesser reductions for ED presentations (26%) and admissions (20%), and increased their use of hospital inpatient bed-days (15%). The recruited COPD patients reported a significant reduction in their symptoms ($P < 0.005$) and the CHF patients reported an improvement in their overall health and quality of life scores ($P < 0.001$). The outcome measures used in this evaluation suggest that an integrated care facilitation model that is patient focussed, provides an education component to promote greater self-management compliance and delivers a continuum of care through the acute and community health sectors, may reduce the utilisation of acute health care facilities and benefit the patient.

Burton CR, Fisher A, Green TL. The organisational context of nursing care in stroke units: a case study approach. Internat J Nurs Stud 2009;46:85–94.

PRIORITY BRIEFING ID 50

Background: Internationally the stroke unit is recognised as the evidence-based model for patient management, although clarity about the effective components of stroke units is lacking. Whilst skilled nursing care has been proposed as one component, the theoretical and empirical basis for stroke nursing is limited. We attempted to explore the organisational context of stroke unit nursing, to determine those features that staff perceived to be important in facilitating high quality care. Design: A case study approach was used, that included interviews with nurses and members of the multidisciplinary teams in two Canadian acute stroke units. A total of 20 interviews were completed, transcribed and analysed thematically using the Framework Approach. Trustworthiness was established through the review of themes and their interpretation by members of the stroke units. Findings: Nine themes that comprised an organisational context that supported the delivery of high quality nursing care in acute stroke units were identified, and provide a framework for organisational development. The study highlighted the importance of an overarching service model to guide the organisation of care and the development of specialist and advanced nursing roles. Whilst multidisciplinary working appears to be a key component of stroke unit nursing, various organisational challenges to its successful implementation were highlighted. In particular the consequence of differences in the therapeutic approach of nurses and therapy staff needs to be explored in greater depth. Successful teamwork appears to depend on opportunities for the development of relationships between team members as much as the use of formal communication systems and structures. A co-ordinated approach to education and training, clinical leadership, a commitment to research, and opportunities for role and practice development also appear to be key organisational features of stroke unit nursing. Recommendations for the development of stroke nursing leadership and future research into teamwork in stroke settings are made.

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PRIORITY BRIEFING ID 57

The purpose of this briefing paper is to aid Stakeholders in prioritising topics to be taken further by PenCLAHRC as the basis for a specific evaluation or implementation research project. This paper was compiled in 2-3 days. The briefing is in four parts:

- General context
- The question in a structured format
- What the research evidence says
- Alignment with PenCLAHRC research priority criteria

QUESTION: What is the most effective way to provide 'activities' or 'meaningful activities' for care home residents?

General context and definitions: The NICE Quality Standard (2013) on mental wellbeing of older people in care homes (QS50) defines meaningful activity in the following way:

> *Meaningful activity includes physical, social and leisure activities that are tailored to the person's needs and preferences. Activity can range from activities of daily living such as dressing, eating and washing, to leisure activities such as reading, gardening, arts and crafts, conversation and singing. Activity may be structured or spontaneous, for groups or for individuals, and may involve family, friends and carers, or the wider community. Activity may provide emotional, creative, intellectual and spiritual stimulation. It should take place in an environment that is appropriate to the person's needs and preferences, which may include outdoor spaces or require adaptations to the person's environment*.

The definition is adapted from SCIE guide 15 Choice and Control, Living well through activity in care homes: the toolkit (College of Occupational Therapists) and expert consensus.

The provision of meaningful activities for care home residents is an indicator of service quality and lack of provision can be a signal of a wider pattern of neglect. However the NICE tailored resource for managers of care homes for older people states that *'activity doesn't have to mean organised activity. It is a myth that the Care Quality Commission (CQC) expects there to be an activities programme and that delivering such a programme is the responsibility of one person – the activity co-ordinator. Activities co-ordinators play an important role, but ensuring that people can spend their time doing things that are meaningful to them is the responsibility of all staff.'* (https://www.nice.org.uk/about/nice-communities/social-care/tailored-resources).

The question in a structured format: In considering this as a research question, we could frame it as following:

Population:	Care home residents and staff
Intervention:	Provision of activities, or meaningful activities or person-centred activities
Comparator:	Alternative models of providing activities
Outcomes of Interest:	Outcomes could include: For residents: quality of life, medication use, quality of engagement between staff and residents, changes in the culture/atmosphere of the care home. For staff: job satisfaction, quality of engagement between staff and residents, staff retention, changes in the culture/atmosphere of the care home.

What the research evidence says: There is extensive guidance highlighting the need for the provision of meaningful activities in care homes and practical advice about the types of activities that might be useful and evidence that particular activities may be effective or not. However, we were unable to identify much published evidence to inform the best ways to do this, or that compares different methods of provision. The processes involved in establishing what an individual resident might consider to be a 'meaningful activity' and the best ways to implement these are unclear. Discussions that took place in the development of this question focussed on the recognition that there is a need to move away from structured, often 'bought-in' activity sessions towards the incorporation of meaningful activities in the day-to-day life of an individual.

A qualitative study involving residents of three care homes, staff and family carers of people with dementia explored concepts of meaningful activity as defined by older people. The main factors that made activities meaningful for residents were based on values and beliefs related to their past roles, interests and routines. Enjoyment was also important and added to the sense of meaningfulness in an activity. All participant groups felt that residents lacked the opportunity to take part in meaningful activities and identified organisational issues as the main reason for this[1].

Some related work conducted in seven nursing homes (193 residents) in the United States, found that residents with dementia were most engaged by one-one socialising with a research assistant, a real baby, personalised stimuli based on the person's self-identity, a lifelike doll, a respite video and envelopes to stamp. Stimuli that were refused most often were a soft toy (animal), colouring with markers, a robotic animal, a childish-looking doll, and an activity pillow. People with comparatively higher levels of cognitive functioning were more likely to be engaged in manipulative and work tasks, whereas those with low levels of cognitive functioning spent relatively more time responding to social stimuli. The authors conclude that understanding the relationship among type of stimulus, cognitive function, and acceptance, attention, and attitude toward the stimuli can enable caregivers to maximize the desired benefit for persons with dementia[2].

A cluster randomised trial conducted in 16 care and nursing homes in London (210 residents) evaluated the effectiveness of an occupational therapist developed training and coaching programme for care home staff on activity provision and resident quality of life for people with dementia. The intervention was aimed at increasing staff skills and changing their attitudes as they came to know residents better and to recognise their potential to engage. Disappointingly, the quality of life of residents was seen to decrease over the course of the study period. The authors attribute the results to a lack of engagement of staff with the intervention, wide variability in how the intervention was implemented, low staff attendance at the training and coaching sessions and patchy provision of additional activities for residents[3].

Ongoing studies: We identified a protocol for a relevant systematic review being conducted at The Dementia Collaborative Research Centre at the Queensland Institute of Technology. The review aims to address the following question: What is the effectiveness of meaningful occupation interventions for people living with dementia in residential aged care facilities (RACFs)? The review will consider randomised and non-randomised controlled trials, quasi-experimental, before and after studies as well as observational study designs. The authors will include studies that evaluate non-pharmacological interventions that are based on occupational or activity interventions considered to be meaningful to the person with dementia, and tailoring the interventions to meet their needs, abilities, interests and/or preferences will be required as part of the study's methods. Such interventions may include reminiscence therapy, diversional therapy and psychosocial interventions. We have contacted the authors of this protocol; they are hoping to submit the paper for publication before Christmas, their findings have not yet been shared publicly and they were unable to provide us with any more detail.

How does this fit with PenCLAHRC research priority criteria?

Size of the health problem: We know from several research studies using Dementia Care Mapping, i.e. the collection of feedback from service users, that many care home environments are regarded as not stimulating for people with dementia. For example, in an evaluation of 17 care homes across three regions of the country, people spent less than 13 per cent of the waking day engaged in any meaningful activity[4]. A subsequent study across 12 care homes suggested that people on average spent only two minutes a day participating in meaningful social interaction[5].

The potential for health improvement: In care home settings where the social needs of residents with dementia remain unmet, the resulting negative social environment in which people are bored and frustrated, can precipitate challenging behavioural symptoms such as restlessness, irritability and aggression and frequently leading to the prescription of sedative antipsychotic medication.

The practicality of the research question: There is clearly variation within the care home community in the knowledge of and confidence in providing a stimulating environment for residents with dementia. It may be possible to explore the meaning of 'meaningful activities' for care home owners, managers and staff, residents with dementia and their families and how to individually tailor activities to residents' needs.

Whether the South West is a good place to do this research: The CQC website suggests there are in the region of 600 care homes in the South West although whether the boundaries are comparable is unclear. There are increasing links between PenCLAHRC academics and the care home community in the South West.

Alignment with local health priorities: This will be different across the South West region and between organisations. Please consider the briefing in line with your local priorities.

GUIDELINES & GOVERNMENT STRATEGIES relating to this area:

NICE Guidance (PH16, 2008). Mental wellbeing in over 65s: occupational therapy and physical activity provides guidance on occupational therapy and physical activity interventions for health care professionals who provide support and care for older people in the community and in residential settings. https://www.nice.org.uk/guidance/PH16/chapter/1-Recommendations

A NICE Local Government Briefing Paper (LGB25) for Older People in Care Homes (2015) calls on councils and health and wellbeing boards to provide meaningful and person-centred activities which can reduce the cost of care, help people retain independence and identity and support Councils to meet their duty of care to residents. This paper encourages care homes to offer regular and/or individual sessions based on occupational therapy principles to identify, construct, rehearse and carry out daily routines and activities that help to maintain or improve their health and wellbeing. Available from http://www.nice.org.uk/advice/LGB25/chapter/What-NICE-says

The College of Occupational Therapists (COT) and the National Association for Providers of Activities for Older People (NAPA) launched a strategic partnership in 2005 in order 'to work together to make access to meaningful occupation a reality for older people' (COT and NAPA 2005). This included the production of a benchmark document that relates to the 'provision and inspection of meaningful occupation for older people' (COT and NAPA 2005). Available from http://www.mentalhealthpromotion.net/resources/activity-provision.pdf

The College of Occupational Therapists (COT) Toolkit Living Well Through Activity in Care Homes (2015) provides practical guidance on the type of activities that might be provided. Available from https://www.cot.co.uk/living-well-through-activity-care-homes-toolkit-0

Relevant abstracts:

Harmer BJ, Orrell M. What is meaningful activity for people with dementia living in care homes? A comparison of the views of older people with dementia, staff and family carers. Aging Ment Health. 2008 Sep;12(5):548-58.

BACKGROUND: Older people with dementia living in care homes often lack appropriate activities. Although homes are expected to offer a range of activities to meet residents' needs, little is known about what makes activities meaningful for people with dementia. This study explores concepts of meaningful activity, as defined by older people with dementia living in care homes, staff and family carers.

METHOD: This qualitative study used focus groups including 17 residents, 15 staff and eight family carers from three care homes. Transcripts of the groups were subjected to thematic content analysis using a grounded theory approach.

RESULTS: Four activity themes emerged -- 'reminiscence', 'family and social', 'musical' and 'individual'. There were also two related themes -- 'lack of meaningful activity' and 'what makes activity meaningful'. Residents found meaning in activities that addressed their psychological and social needs, which related to the quality of the experience of an activity rather than specific types of activities. In contrast, staff and family carers viewed activities that maintained physical abilities as meaningful.

CONCLUSION: People with dementia staff and carers had differing views about what made activities meaningful. Organisational limitations and social beliefs limited the provision of meaningful activities for this population. The study also indicates areas for improving activity provision in care homes.

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PRIORITY BRIEFING ID 60

The purpose of this briefing paper is to aid Stakeholders in prioritising topics to be taken further by PenCLAHRC as the basis for a specific evaluation or implementation research project. This paper was compiled in 2-3 days. The briefing is in four parts:

- General context
- The question in a structured format
- What the research evidence says
- Alignment with PenCLAHRC research priority criteria

QUESTION: Can targeted, multi-professional interventions to improve person-centred prescribing in primary care lead to improved patient activation, reduced medicines waste and improved outcomes?

General context and definitions: Getting the most from medicines (medicines optimisation) for both patients and the NHS is becoming increasingly important as more people are taking more medicines. Medicines, prevent, treat or manage many conditions and are the most common intervention in healthcare. However, it has been estimated that between 30% and 50% of medicines prescribed for long-term conditions are not taken as intended[1]. This issue is worsened by the growing number of people with long-term conditions.

Medicines optimisation is about ensuring that the right patients get the right choice of medicine, at the right time. By focusing on patients and their experiences the goal is to help patients to improve their outcomes, take their medicines correctly, avoid taking unnecessary medicines, reduce wastage of medicines, and improve medicines safety. The medicines optimisation approach requires multidisciplinary team working to individualise care, monitor outcomes, review medicines frequently and support patients when needed.

The question in a structured format: In considering this as a research question, we could frame it as following:

Population:	Individuals requiring prescribed medications
Intervention:	Targeted, multi-professional interventions to improve person-centred prescribing in primary care.
Comparator:	Usual care.
Outcomes of Interest:	Patient activation, medicines waste and improved outcomes.

PRIORITY BRIEFING ID 60

What the research evidence says: This question has similarities with the following question that was prioritised in December 2014:

In multi-morbid patients taking at least three prescribed medications, can a new model of prescribing reduce treatment burden and optimise individually appropriate medicines uses?

In response to the adoption of this question by PenCLAHRC, the following pieces of work are underway:

- Preparation of a funding bid for a Programme Grant to develop and trial a person-centred prescribing intervention in primary care. The bid is being led by Associate Clinical Professor Joanne Reeve from CLAHRC West Midlands and will include several PenCLAHRC academics (Nicky Britten, Janet Heaton, Richard Byng), members of PenPIG and collaborators from elsewhere (Professor Janet Krska from Medway School of Pharmacy). The aim is to submit the bid in April 2016.

- PenCHORD, the Operational Research Team of PenCLAHRC, has undertaken an innovative exploratory simulation modelling project that seeks to address the question:

  Can agent-based simulation be used as a means of determining the optimal set of medications to prescribe to adults with type 2 diabetes and asthma, such that their treatment burden is minimised, the clinical benefit of the medication is maximised and wasted costs from unused medication or additional hospital visits is minimised?

  Agent-based simulation is a computer simulation method in which the behaviours, characteristics, interactions and motivations of individuals within a system are explicitly modelled, in order to gain a better understanding of population-level behaviours. The principle aim of this project is to develop a proof-of-concept agent-based simulation that demonstrates how we can model the adherence behaviours of those taking multiple medications, and therefore better inform prescribing practice by being able to compare the levels of adherence and states of health of a population taking various prescription combinations. The project team includes members of PenPIG, a pharmacist, a GP, the Academic Health Science Network (AHSN) and polypharmacy researchers within PenCLAHRC. The project has completed its development stage and is seeking funding to enable exploration of applying the model using real world data.

Discussions with the teams involved in the ongoing work confirm the considerable overlap with the currently proposed uncertainty. However, the issues of person-centred prescribing and medicines optimisation are clearly priorities among PenCLAHRC stakeholders. Improving the understanding of current interventions being used in the PenCLAHRC region to optimise prescribing is a potential area for work that could complement the ongoing projects. This might involve mapping existing initiatives in terms of skills mix, cost, resource use, team working, healthcare setting and outcome measures and interviews to explore the views and experiences of the individuals involved in their delivery.

How does this fit with PenCLAHRC research priority criteria?

Size of the health problem: Getting the most from medicines (medicines optimisation) for both patients and the NHS is becoming increasingly important as more people are taking more medicines. It has been estimated that between 30% and 50% of medicines prescribed for long-term conditions are not taken as intended[1]. The number of people in the UK diagnosed with more than one long term condition (multi-morbidity) is expected to rise to 2.9 million by 2018[2]. Data from the Health and Social Care Information Centre shows that between 2003 and 2013 the average number of prescription items per year for any one person in England increased from 13 to 19 (http://www.hscic.gov.uk/home).

The potential for health improvement: The cost of NHS medicines and appliances supplied in primary care is in excess of £8 billion every year. A significant proportion of these drugs are wasted because they are either not taken correctly or because they are never taken at all. It is estimated that up to 50% of patients do not take their medications correctly. Patients who do not take their medicines correctly are less likely to receive the intended health benefits and more likely to suffer complications with significant implications for their health and for NHS finances. The cost of hospital admissions as a result of incorrect medicine usage could be up to nearly £200 million a year. Many medicines are simply never taken. A recent York Health Economics Consortium and School of Pharmacy report found that NHS primary and community care prescription medicines waste costs £300 million a year. This figure includes £90 million worth of unused prescription medicines stored in individuals' homes at any one time, £110 million returned to community pharmacies over the course of a year, and up to £50 million worth of NHS supplied medicines that are disposed of annually by care homes[3].

The practicality of the research question: The question fits well within the PenCLAHRC Patient-Centred Care theme and there is interest locally in prescribing and user-led approaches. The suggested area of focus would complement the existing plans to obtain funding to trial a patient-centred prescribing intervention.

Whether the South West is a good place to do this research: This work follows on from a previous review of the literature, funded by PenCLAHRC and carried out in Exeter and builds on the two projects described above.

Alignment with local health priorities: This will be different across the South West region and between organisations. Please consider the briefing in line with your local priorities.

GUIDELINES & GOVERNMENT STRATEGIES relating to this area:

NICE Guidance on medicines optimisation: the safe and effective use of medicines to enable the best possible outcomes was published in March 2015[1]. Recommendations relevant to this research question include the use of individualised, documented self-management plans to support people who want to be involved in managing their medicines, the use of patient decision aids in consultations involving medicines and the use of medicines related models of organisational and cross-sector working.

The King's Fund report – Polypharmacy and medicines optimisation: Making it safe and sound – highlights many of the issues surrounding polypharmacy and offers practical guidance to clinicians and others in avoiding inappropriate prescribing[4].

The Royal Pharmaceutical Society published guidelines in May 2013 – 'Medicines Optimisation: Helping patients to make the most of medicines. Good practice guidance for healthcare professionals in England'[5]. This guideline represents a collaboration between patients and the health professionals that care for them. It sets out four simple but important principles of 'medicines optimisation'; aim to understand the patient's experience, make evidence-based choices of medicines, ensure medicines use is as safe as possible, make medicines optimisation part of routine practice.

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