Using co-production to improve patient carer and staff experiences in health care organizations: a multi-centre, mixed methods evaluation in inpatient stroke units.

'CREATE' **C**ollaborative **R**ehabilitation **E**nvironments in **A**cute s**T**rok**E'**:

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Research Summary

We know that despite improved stroke care in the UK there are still many patients and families who experience a high burden of disability from stroke (Intercollegiate Stroke working Party,(ICSWP) 2012; McKevitt et al., 2011). National audits have shown a reduction in length in stay in hospital and an increase in early supported discharge uptake in the last seven years for patients with mild disability but comparatively, patients with more severe disabilities are residing on stroke units for more than two weeks (Cloud, Hoffman and Rudd, 2013).

Rehabilitation is an integral part of post stroke care which if started early is associated with improved outcomes in patients with stroke disability (Langhorne, Bernhardt and Kwakkel, 2011). However audits continue to highlight limitations of targets to provide rehabilitation in hospital at an intensity and frequency that is beneficial (National Sentinel Stroke Clinical Audit, 2010; 2012). The strong focus on therapy provision and

meeting national targets is one solution (National Institute for Health and Care Excellence 2013). However minimal efforts have been made to explore organisational contexts and processes which may contribute to therapeutic activity in a broader sense on inpatient stroke units and address the intractable problem that most patients are spending the majority of their time inactive and disengaged (Janssen et al.,2013;NHS Improvement (Stroke) Mind the Gap, 2011).

There is a need for more creative responses to the problem of very low activity levels in inpatient stroke unit rehabilitation. We will engage patients, families and staff as active partners in the review and redesign of the environment, practices and customs contributing to inpatient stroke care, in order to increase supervised and independent therapeutic patient activity. We will evaluate the feasibility of using a co-production approach to redesign rehabilitation related care processes in acute stroke units (Bate and Robert, 2007, Tsianakas et al., 2012; Needham and Carr, 2013, Robert et al, 2015). Our evaluation will increase evidence about 1) whether co-production approaches can be used to improve accessibility and quality of therapeutic activity in acute stroke care and 2) whether the co-produced solutions in one unit are transferrable to other acute inpatient services.

Aims and Objectives

Aim

To evaluate the feasibility and impact of patients, carers and clinicians co-producing and implementing interventions to increase supervised and independent therapeutic patient activity in acute stroke units.

Our objectives are to:

1. Complete a rapid synthesis to update the evidence on the efficacy and effectiveness of co-production as an approach to quality improvement in acute healthcare settings
2. Using qualitative methods and behavioural mapping, study the impact of developing and implementing co-produced interventions on the quality and amount of therapeutic activity on up to four acute stroke units.
3. Study (using Normalisation Process Theory) the process of implementing co-produced interventions in acute stroke units and how it is perceived by staff, patients and carers involved.
4. Collect data pre and post implementation of co-production interventions using a stroke specific Patient Reported Experience Measure (PREM) and a Patient Reported Outcome Measure (PROM) from cohorts of patients to establish if there are differences in patient reported experiences and outcomes for the time periods studied.
5. Critically review pre and post implementation data from the Sentinel Stroke National Audit Programme (SSNAP) on the quality of stroke care in the participating acute stroke units.
6. Evaluate the feasibility of using co-produced interventions developed from two acute stroke units and implementing these in two further stroke units over a

shorter time.

7. Identify factors and organizational processes which act as barriers or facilitators to implementing and embedding co-produced interventions in acute stroke units and provide recommendations on how these might be addressed and delivered in other acute healthcare settings for (example elderly care, trauma and orthopaedic units)

Background and Rationale

Stroke management; persistent concerns

Recent decades have seen significant developments in the organisation and management of stroke, particularly following the implementation of the National Stroke Strategy by the Department of Health in 2007 (Department of Health. 2007; Sandercock, 2012). The role of organised stroke care is well established in significantly improving outcome after acute stroke (Govan 2008; Stroke Unit Trialists' Collaboration, 2013). However whilst incidence is falling and case fatality improving, prevalence continues to rise (Lee, Shafe and Cowie, 2011, Wolfe, Mckevitt and Rudd, 2014). UK trends are reflected in a recent global study showing the absolute number of people who have a stroke every year, stroke survivors, related deaths, and the overall global burden of stroke are great and increasing (Feigen, 2013). Estimates suggest there are in the region of 900,000 people living with the consequences of stroke, costing the UK economy approximately £8.9 billion per year (5% of the NHS budget) of which £4 billion is spent on treatment costs including organised inpatient stroke unit care (Saka et al 2009). Despite large scale service reconfiguration such as the London and Greater Manchester models which have reduced length of stay to ~17 days (Fulop et al 2013), patients on acute stroke units, who are often the most disabled, are likely to spend at least 50-60% of their time inactive and disengaged (National Sentinel Stroke National Audit Programme 2013; Bernhardt et al 2004 and 2007, Huijben-Schoenmakers et al 2009).

Intensive medical care and diagnostic testing now characterises the acute management of stroke, but it is suggested that stroke should be regarded as a 'long term condition' with outcome determined by collaborative care, rehabilitation and self-management (Teasell et al 2014; O'Neill et al.,2007). Multi-disciplinary stroke teams typically include doctors, nurses, social workers, therapists, dieticians and psychologists, but Occupational Therapists (OTs), Physiotherapists (PTs), and Speech and Language Therapists (SLTs), are recognized as the central providers of rehabilitation who aim to maximise independence and prevent further complications after a stroke (Dewey et al 2007). The component of acute stroke care most highlighted as likely to improve long term outcome is rehabilitation. These assertions are informed by research that has shown that early activity post stroke not only improves overall prognosis but can reduce disability (Janssen, et al., 2013). This is reflected in the following statement from the Department of Health's (2007) National Stroke Strategy;

"Rehabilitation after stroke works. Specialist co-ordinated rehabilitation, started early after stroke and provided with sufficient intensity, reduces mortality and long-term disability." (Department of Health 2007).

The ICSWP National Clinical Guidelines for Stroke (2012) and the recent National Institute for Health and Care Excellence (NICE, 2013) Stroke Rehabilitation guidance have facilitated greater knowledge mobilisation of high quality research evidence in order to provide specific guidance on the intensity of rehabilitation. The 4th edition of the National Clinical Guidelines for Stroke (NCGS) was published in 2012 and includes 28 'key recommendations' which if followed would have the most impact on the quality of stroke care. One recommendation comprised a clear statement about the recommended 'dose of rehabilitation' and states;*"Patients with stroke should be offered a minimum of 45 minutes of each appropriate therapy that is required, for a minimum of 5 days per week, at a level that enables the patient to meet their rehabilitation goals for as long as they are continuing to benefit from the therapy and are able to tolerate it" (ICSWP, 2012: xiii)*

While this recommendation is widely known about, it has often been interpreted primarily as a responsibility of therapists whereas the ICSWP (2012) guidelines also recommend that: *'The team should promote the practice of skills gained in therapy in the patient's daily routine in a consistent manner and patients should be enabled and encouraged to practise that activity as much as possible.'*

Similarly, in Mind the Gap, report (NHS Improvement Stroke, 2011:10), it was recommended that: *'Therapists should increase involvement with the patient and the wider team, and where appropriate should include nursing staff and the family in promoting a continuous rehabilitation culture. This can also support the patient towards self-management in the longer term*.'

Neither of these recommendations appears to be widely known and there is little evidence that they are widely adopted. Experience Based Co-Design (EBCD) (Bate and Robert 2007b) offers an opportunity for patients, carers and staff to co-produce interventions to address these recommendations and as stated by Sir Roger Boyle- *'make rehabilitation <u>the basis</u> of the patient's day, as opposed to an infrequent part of it' (*Boyle, 2011*)*

<u>The challenge of rehabilitation provision in acute stroke care</u>

An urgent need for changes in acute stroke unit rehabilitation provision was generated by research describing stroke care across 4 European countries (Putnam et al., 2006). This study indicated higher or equivalent therapist staffing levels but relatively low levels of activity by stroke patients in the UK. Importantly this research showed there was a direct impact on outcome post stroke with higher levels of dependency in the UK stroke population (De Wit, 2005, Putnam, 2006). Compliance with national targets designed to increase rehabilitation intensity and frequency has been monitored by Sentinel Stroke National Audit Programme (SSNAP) since 2012. Analysis of national audit data for the period July to September 2014 still confirms variation amongst units in a) the proportion of patients considered to require therapy; b) the median number of minutes of each therapy provided; and c) overall performance against the therapy target. On average, the target of 45 minutes of therapy for a minimum of 5 days a week was not being met. The most recent National SSNAP report (July – September 2014) reported that although progress has been made, there was still a need for further progress in the intensity of therapy provided. For the period of the report, the median number of

minutes of therapy on the days that patients got any was 40 minutes for OT, 33 minutes for PT and 30 minutes for SLT. However, the report highlighted that there are days when patients should be getting therapy and when they get none. The median percentage of days as an inpatient on which therapy was received was 59% for OT, 68.5% for PT and 39.9% for SLT. This raises renewed concerns regarding the amount of time patients are spending inactive on stroke units. The wide variation in assessment of appropriateness for therapy, quantity of therapy received and spread of therapy across the week is unexplained and raises two important questions;

Firstly whether the 'dose of therapy' is the right answer when therapy staffing levels are unlikely to increase, and it is likely that the number of patients 'deemed appropriate for active therapy' will not change. Moreover, the case mix on stroke units is changing and patients with mild disability are being discharged earlier with the expansion of early supported discharge services whilst patients with more complex and severe levels of disability are likely to require a longer in-patient stay (Cloud et al., 2013). We question whether the continuing and narrow focus on 'dose of therapy' is counterproductive. Recent research in Australia concluded that dose driven interventions including circuit class therapy and seven day-week therapy increase amounts of therapy provided but do not increase meaningful patient activity outside of therapy sessions (English et al 2014); and called for more research into drivers of activity outside therapy sessions.

Secondly we question whether current models of 'therapist' focused inpatient stroke rehabilitation and reliance on 'waiting for therapy to be delivered' may foster dependency and inactivity, and are therefore at odds with promoting independence and self-management in hospital and after discharge (Skarin et al., 2013; Peiris et al., 2011). The paradox of a highly medicalised environment such as an acute stroke unit which could be counterproductive to promoting independent therapeutic activity, self-directed practice and self-management beyond secondary care has been questioned (Huijben-Schoenmakers, Gamel, and Hafsteinsdóttir, 2009; Jones and Riazi, 2010; Bernhardt 2004). Emerging evidence suggests in acute healthcare environments, staff, carers and patients could do more to enable an increase in supervised and independent therapeutic activity, which has the potential to expedite discharge and decrease dependency on health and social care services in the longer term (Galvin et al 2011, Peiris et al 2011, Janssen et al, 2013). Studies have identified short term methods to increase therapeutic activity but these are driven by the perspectives of professionals with little evidence patients and carer involvement in the development and implementation interventions.

Policy importance of patient centred service improvement

Improving patients' experiences and putting patients at the centre of everything is a key aim for the NHS. NHS England's most recent business plan, 'Putting patients first' draws on a previous 'Call to Action' strategy which highlighted citizen participation and empowerment as one of six characteristics of a high quality sustainable NHS (NHS England, 2014a). The value of innovations which build upon patients' rights to drive up quality of experience is now embedded into much of recent health policy. NHS England's (2014b) Five Year Forward View sets out how the NHS must change,

arguing for a more engaged relationship with patients and carers in order to promote wellbeing and prevent ill-health. To improve patients' experience, NHS policy makers seek to encourage development of new relationships between patients, carers and clinicians. These relationships are to be based on working together, in equal partnership, not only to make personal care decisions and agree care plans, but also to develop partnerships where patients, carers and clinicians are involved in the co-design, co-commissioning and co-production of healthcare services (NHS England, 2014).Treating patients respectfully as customers and putting their interests first is one of the key measures set out in the NHS Commissioning Board's document ' Everyone Counts' which states; *'We want to put patients in control and to offer them a world class customer service. For this reason, we will prioritise innovation in developing services around the needs of patients and the public' [section1.22].*

The National Patient Advisory (NPA, 2013) in their post Francis report reasserts the priority of working with patients and carers to achieve healthcare goals. However, the report similarly warns against the overuse of quantitative targets as a method to drive up quality. As stated in the NPA report, *'goals in the form of such targets can have an important role en route to progress, but should never displace the primary goal of better care.' [point 4, page 10]*

The NHS is a complex system and to focus on patients' experience when resources and workforce are under pressure is a fundamental and critical challenge. The 'Point of Care' programme defines patients as a product of the whole system of care, and highlights that 'Patients' stories and patients' complaints remind us of the importance of seeing the person in the patient and bringing patients' experience alive.' (Goodrich and Cornwell,2008)

Using co-production to improve therapeutic activity on an acute stroke unit.

Engaging patients and staff in service redesign to address the lack of therapeutic activity outside of planned therapy meets the remit of the HS&DR programme and responds to policy directives to increase public involvement (Keogh, 2012, NHS England , 2014). Co-production methods, harness the power of patients, carers and staff to make changes they know and care most about (Bate and Robert 2007; Tsianakas et al., 2012; Needham and Carr, 2013). In the broadest sense, co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services and their families (Needham and Carr, 2013). The central idea in co-production is that people who use services are hidden resources, not drains on the system, and that no service that ignores this resource can be efficient. Advocates of co-production see it as a different way of thinking about public services, with potentially transformational consequences, as people who use services take control of defining and managing their care:

The biggest untapped resources in the health system are not doctors but users. […] We need systems that allow people and patients to be recognised as producers and participants, not just receivers of systems. […] At the heart of [co-production], users will play a far larger role in helping to identify needs, propose solutions, test them out and implement them, together. (Cottam & Leadbeater, 2004, pp.16-22)

Experience-based Co-design is an approach to improving healthcare services that combines participatory design and user experience design to bring about quality improvements in healthcare organizations. It originated in 2005/06 as a participatory action research approach that explicitly drew on design theory (Bate and Robert, 2007a) and was first piloted in a head & neck cancer service at Luton & Dunstable hospital (Bate and Robert, 2007b). Through a co-production process EBCD entails staff, patients and carers reflecting on their experiences of a service, working together to identify improvement priorities, devising and implementing changes, and then jointly reflecting on their achievements. A recent international survey of completed, ongoing, and planned EBCD implementations in healthcare services found that at least 59 EBCD projects have been implemented following the pilot project in 2005/06, with at least a further 27 projects in the planning stage (Donetto et al., 2014). The number of projects appears to be growing year on year but with a small number of notable exceptions (Ledema et al., 2010, Tsianakas et al., 2012, Piper et al., 2012, Bowen et al., 2013), robust evaluation studies of EBCD projects remain scarce (Voorberg et al 2014). There have been no examples of EBCD being used in acute stroke services to date.

What might an co-produced interventions on a stroke unit deliver?;

As part of the Experience-based Co-design (EBCD) approach, participants will be asked to think creatively about how post-stroke care in their stroke units could be redesigned to increase supervised and independent therapeutic activities. The aim is to consider rehabilitation as a joint enterprise which draws on both lay experience and professional expertise, to design practical strategies which are not solely reliant on delivery by professionals. As stroke impacts on physical, psychological and social aspects of peoples' lives, we anticipate intervention(s) developed will include components related to each of these areas. Evidence suggests environmental enrichment, including communal and individual provision of accessible activity based resources, supported use of computers, recreational games, reading material, audio books and music can lead to improved social, cognitive and functional outcomes (Särkämö et al., 2008; Ada et al., 2006; Janssen et al., 2010; 2012; 2013). Support to engage in activities can also be provided by family, friends and volunteers. As part of a multicomponent intervention, structured group activities focused on communication after stroke, or task specific activities including breakfast groups, exercise and relaxation groups can also be run by activity coordinators, trained volunteers or rehabilitation assistants; carers/relatives can also participate (Kent, 2012; De Weerdt, 2001). Practice of this, kind supported by family members, has been shown to increase functional activity in single centre trials (Galvin et al, 2011) with other studies identifying family members' interest in participating in supporting) patient activity and practice (Lawler et al (2015).

The majority of the elements outlined above could be adapted for use in other acute healthcare and rehabilitation environments. These require changes in staff and patient behaviour and use of space and existing resources within units rather than substantial financial investment. There is existing evidence that environmental and social enrichment is beneficial in dementia care environments and elderly care environments; similarly the benefit of increased activity levels in acute rehabilitation settings has been demonstrated (Janssen, 2010; 2012; 2013; Peiris, 2011; Galvin, 2011). The transferability of these elements to other NHS settings will require local interpretation

and some adaption for different patient groups. The evaluation of the EBCD and co-production process will provide valuable direction for staff in related acute healthcare and rehabilitation environments about the process of using such co-production approaches and to determine how their acute services may be redesigned for patient benefit.

Unique to this study we will draw on design innovation which requires genuinely workable solutions that use a process of co-designing and prototyping which is iterative. This extended type of engagement also recognises the iterative nature of stakeholder involvement, of the gradual crafting, refinement and emergence of innovative interventions. We will aim to make rehabilitation the basis of the patient's day. Developing cultures of continuous rehabilitation is likely to require early and sustained involvement of the whole multi-disciplinary team, some revision of their working practices and development of practical ways to engage and involve patients and their families. This will increase evidence about 1) the feasibility of using co-production approaches to increase supervised and independent therapeutic activity in acute stroke care and 2) whether such approaches are effective and are transferrable to other acute inpatient services.

Design and conceptual framework:

The design is a mixed method, case comparison evaluation. We will conceptualise the development and implementation of the co-produced interventions as an organisational and social process involving interaction between both the creators and the users of knowledge (Moore et al 2014). Translating the knowledge arising from health services research into practice through the implementation of service innovations remains a key challenge in the drive to improve the quality of health care. A number of different models of knowledge translation have been proposed in the literature, such as the Stetler model the PARIHS framework, the Ottawa model for Research Use, and the Knowledge to Action framework, among others (Brownson et al 2012). Organisational and social processes will largely determine whether new knowledge is implemented in practice. Although the frameworks mentioned above have become increasingly sophisticated - and recent models take into account the socially situated nature of knowledge translation practices - the influence of context has not been fully accounted for in these models.

Recognizing the limitations of much of the existing empirical literature for making recommendations to practitioners, we will use Normalization Process Theory (Murray et al 2010, May et al., 2011) to study the implementation and assimilation of the co-produced interventions in the local context of our study settings. NPT identifies four generative mechanisms that explicate how interventions are embedded and 'normalised' within routine care. These are: coherence, cognitive participation, collective action and reflexive monitoring; in essence these mechanisms represent what participants 'do' to get the required work done successfully. In lay terms, the mechanisms can be understood as participants making sense of a new or different way of working, committing to working in that way, making the effort and working in that way and undertaking continuous evaluation, and if necessary, making adjustments to bring about a situation where what was once a new and complex intervention becomes a

normal part of everyday practice activity. We will introduce and use NPT methods prior to Phase 2 (see below) and throughout the remainder of the programme of research.

Research Plan/Methods
Our research questions focus on 1) The experience of staff, patients and carers in acute stroke units using a co-production approach to develop and implement interventions to increase supervised and independent therapeutic activity, 2) the factors and organisational processes which act either as barriers or facilitators to successfully implementing, embedding and sustaining co-produced quality improvements in acute care settings, and how these can be addressed and enhanced.

Research Plan/Methods
The research will be undertaken in three phases. In phase 1 we will complete a rapid evidence synthesis to update the evidence on the efficacy and effectiveness of co-production as an approach to quality improvement in acute healthcare settings. In phase 2 we will use Experience Based Co-design as our co-production methodology to design and implement interventions and evaluate the impact in 2 stroke units. Following a formal 'break point' in the study (see below), in phase 3 we will proceed to implement the co-produced interventions developed in phase 2 in a further 2 stroke units.

Phase 1 We will complete a rapid evidence synthesis to update the evidence on EBCD as a methodology to increase the efficacy and effectiveness of co-production approaches in acute healthcare settings. Our central question will ask *'What is known about the efficacy and effectiveness of co-production approaches in acute healthcare?'.* The rapid evidence synthesis methodology and methods will be clearly documented to ensure the review can be replicated (Gannan et al., 2010). The completeness of the review will be constrained by the availability of relevant published research, policy and grey literature within the last 10 years (2005-2015). The search strategy will include a focus on sensitivity of terms relating to co-production in order to identify and capture the most relevant and up to date research, policy and grey literature. A systematic process will be used for item searching, selection, screening, coding, critical appraisal and synthesis, building on methods outlined by NFER (2011).

Phase 2 The parallel process evaluation, underpinned by NPT methods commences here and draws on planned observational and interview data generated in phases 2 (and 3).

The study will be conducted in two acute stroke units in Phase 2, one in the London area and one in Yorkshire. Sites in London and Yorkshire will be selected if they are classified as either 'a routinely admitting stroke unit' with Hyper Acute Stroke Units (HASU) + Acute stroke units (ASU) or a 'non-routinely admitting stroke unit (ASU)' and have been named in team results spreadsheet for 72 hours and 7 days. In London there are just 8 routinely admitting HASUs and patients are repatriated after 72 hours to an ASU either on the same site or at another site. In Yorkshire there is a single HASU with a co-located ASU. The co-produced interventions will be developed and tested for

patients on ASUs (post 72 hours). We plan to recruit ASUs either co-located as in Yorkshire, or on separate sites as in London, as we believe this ASU approach is more representative of stroke services nationally. Site selection will take into account the number of admissions per month and the size of stroke team and whether they meet the requirements of a specialised stroke service set out in the 2012 National Clinical Guidelines for Stroke section 3.2. Our criteria will include sites that have returned 72 hours results and discharge data in the Sentinel Stroke National Audit Programme (SSNAP) quarterly report achieving case ascertainment above the 90% threshold (SSNAP report July- September 2014). This is so that we can be sure of the completeness and accuracy of SSNAP data. We aim to recruit stroke units with evidence of previous participation in research ensuring that these units have an interest in delivering the research planned.

Phase 2 sites will take part in a full cycle of developing and implementing co-produced interventions informed by the stages of Experience Based Co-Design (EBCD) (Bate & Robert, 2007; Robert, 2013). In order to evaluate the feasibility and impact of patients, carers and clinicians co-producing and implementing interventions to increase supervised and independent therapeutic patient activity in acute stroke units, we will evaluate factors influencing co-production and implementation processes in the two units through a qualitative process evaluation and incorporate analysis of implementation and assimilation using Normalisation Process Theory (NPT). Methods for evaluation of impact on therapeutic activity and experiences of patients, carers and staff of the co-produced interventions are detailed in the sections which follow; these will inform progression to phase 3.

Phase 3. If the phase 2 evaluation data supports progression to phase 3, the same co-produced interventions developed for phase 2 will be adapted and implemented in two further acute stroke units (in London and another unit in Yorkshire), baseline and post implementation data will be collected using identical methods**.**

DATA COLLECTION (in more detail)

Pre-implementation (Months 3-6) Collection of baseline data pre implementation of the co-production approach will be from three sources; 1) SSNAP data routinely collected by stroke unit teams* on unit performance including domains 5-7 in the clinical audit in the last reported period prior to the study; 2) Researcher collected measures will include non-participant observations of unit processes and practice, behavioural mapping to monitor amount and type of patient activity, and PREM and PROM data from a cohort of patients discharged from the participating London and Yorkshire stroke units in the 3 months prior to commencement of the study. We have utilised this joint approach to data collection in order to minimise the time burden of measurements for patients, carers and staff. These measures and processes will be repeated at the end of Phase 2. We have estimated based on stroke admission data across London and Yorkshire that it will be possible to collect baseline data from an independent sample of 30 patients from each unit pre and post implementation.

Anonymised patient data is routinely submitted every three months by all stroke units participating in the Sentinel Stroke National Audit Programme (SSNAP). These data

include NIHSS score, an indicator of stroke severity, recorded at arrival and 24 hours after thrombolysis if administered, length of stay, whether therapy was required, if so on how many days this was received and how many minutes in total were provided (for OT/PT/SALT); the Modified Rankin Score, a measure of the degree of disability or dependence in the daily activities of people following a stroke is also recorded at discharge. These data will enable comparison of the level of patient dependency during the periods of study; this is a factor which may influence activity levels which could be achieved.

Researcher collected:

Patient reported outcome (PROM) and patient reported experience measures (PREM), will be used with up to 30 patients cared for in each unit in months 3-6 (the pre-intervention stage of the study). The PROM incorporates validated measures including the Oxford Handicap Scale, the Subjective Index of Physical and Social Outcome (SIPSO), and the EQ5D. The PREM was developed by Kneebone et al (2012) and is a validated tool for patient reported experience of neurological rehabilitation. PROM/PREM data will be collected via postal survey from patients that were in-patients during pre and post EBCD intervention periods.

Non-participant observations in the stroke unit will take place after project set up and before behavioural mapping data collection. In preparation for the co-production processes, researchers will undertake non-participant observations in each stroke unit over a period of two weeks. An observational framework developed for use in in a previous process evaluation of caregiver training (Clarke et al, 2013), will be used to record observations of the stroke unit contexts, organisational processes, staff and patient interactions and instances of planned and unplanned therapeutic activity, including timetabled therapy occurring on a one to one or group basis. Observations will take place at different times of the day, evenings and on at least one weekend day in order to develop understanding of how activity may vary across a range of times and different days of the week. Prior written informed consent will be sought from all potential participants with process consent also being confirmed prior to each patient or staff specific observation.

Behavioural mapping will be employed to record the ‘type and number’ of supervised and independent therapeutic patient activities evident outside of planned therapy, using an approach successfully utilised in two recent stroke rehabilitation studies concerned with increasing patient activity (Askim et al.2014; Janssen et al 2014). In weeks, 3, 5 and 8 of Phase 2 all patients on the stroke unit will be screened to determine whether behavioural mapping would be feasible. A minimum of 4 and maximum of 8 patients who meet the inclusion criteria and are able to provide consent on the day before the observation will be observed at 10 minute intervals between 8am and 5pm over one single day in each week. This will allow for up to 55 observations in each unit per day. The days of the week when behavioural mapping is undertaken will vary to allow for possible variation in activities on different days of the week. Observations will last up to one minute for each patient during which the level of activity will be recorded on a structured observation schedule with categories of activity defined by the research team in advance. We anticipate these categories will include up to 12 different forms of

physical activity (for example: a) no active motor supine; b) no active motor on left side; c) no active motor on right, side; d) sit support in bed; e) sit support out of bed; f), transfer with hoist; (Askim et al 2011, 2014).

As we are also interested in social and cognitive activity rather than only with physical functional activity, researchers will also have categories for non- physical leisure activity that involves engagement in a mental task e.g. reading a book or listening to music/the radio, or therapist prescribed communication and language or occupational therapy activity (this could be singing, reciting phrases or rhymes, or using the wii for gaming related to upper limb use) and also for social interaction e.g. talking with others. Researchers will also record location of the activity and who was present during the interaction. (Askim, et al 2014, Janssen et al, 2014; Bernhardt et al 2008,).

Development of co-produced interventions and implementation (months 7-16)
Development and implementation of the co-production process interventions will follow the stages set out in the online EBCD toolkit. Through a 'co-design' process the study will enable staff, patients and carers to reflect on their experiences of the acute stroke unit, working together to identify improvement priorities, devising and implementing changes, and then jointly reflecting on their achievements.

The EBCD cycle typically takes 9 to 12 months (Bate & Robert, 2007) - is divided into six stages: (1) setting up the project; (2) gathering staff experiences through observational fieldwork and in-depth interviews; (3) gathering patient & carer experiences through observation and 12-15 filmed narrative-based interviews; (4) bringing staff, patients and carers together in a first co-design event to share - prompted by an edited 20-30 minute 'trigger' film of patient narratives - their experiences of a service and identify priorities for change; (5) sustained co-design work in small groups formed around those priorities (typically 4-6); and (6) a celebration and review event (Robert and Cornwall, 2013).

Semi-structured interviews with patients and carers will be used to elicit their perceptions and recall of opportunities for and experiences of supervised and independent therapeutic activity in the stroke units. Between 10 and 15 patients post discharge from each unit will be interviewed and filmed, at a time after discharge sufficient to begin the process of adaptation to life at home, but sufficiently close to their inpatient care episode to allow reasonably accurate recall. These filmed interviews will help identify and represent trigger/touch points to be used in the staff and patient feedback events.

Semi-structured interviews with staff: These will be conducted with a purposively sampled group of up to 15 members of staff in each unit. Staff with a range of stroke unit experience, from the three therapy professions and other stroke team members, at different grades will be interviewed and filmed to elicit perceptions of rehabilitation and the opportunities for and experiences of supervised and independent therapeutic patient activity. In addition, staffs perceptions of organisational process which influence therapeutic activity with patients, carers and with other members of the stroke team will

be explored together with their views on areas where additional supervised and independent therapeutic activity might be considered by the stroke teams.

Data from behavioural mapping, non-participant observations and interviews will contribute directly to the co-production meetings identified and will inform the co-design process (see below). Interview and non-participant observational data will be thematically analysed and 25-30 minute 'trigger' films developed to generate trigger/touch points about opportunities and experiences of supervised and independent therapeutic patient activity for use in staff and patient feedback events.

Feedback Events: Two staff feedback events (Yorkshire and London) and two patient and carer feedback events (Yorkshire and London) will be held. At each the trigger films will be used to facilitate discussion about interventions which could be developed to increase supervised and independent therapeutic patient activity. One final shared event at each unit will be held bringing staff, patients and carers together in a first co-design event to share - prompted by the edited 20-30 minute 'trigger' film of patient narratives and the discussions at the staff and patient feedback events - their experiences of a service and identify priorities for change. Areas of improvement and new interventions will be agreed jointly and sustained using small groups formed around those priorities. We anticipate requiring at least 3 further co-design meetings to be held in each site to enable implementation and sustaining of new co-produced interventions. EBCD has not previously been used in an acute stroke unit and there is no archive of filmed narratives with stroke rehabilitation patients currently available, hence the need to undertake film led narrative interviews with patients and carers in the two sites. The films will be available to be used to facilitate implementation of intervention in phase 3 if necessary.

Post implementation data collection Months 17-21

Researcher collected and routinely collected outcome data. In this phase data will be collected from a second (independent) sample of 30 patients using identical measures and methods as those in the pre-implementation part of Phase 2. This will include repeating non-participant observations, behavioural mapping and collecting SSNAP/PROM/PREM data, and interviews with a sample of staff, patients, carers involved in EBCD

Celebratory event. Month 20. An important part of the EBCD process is the opportunity for staff patients, carers and researchers to come together and celebrate their involvement with developing, implementing and sustaining the co-produced interventions (Bate & Robert, 2007; Robert & Cornwall, 2013). This will take place in month -20 regardless of the decision to proceed to phase 3.

Break Point Month 20-22: Phase 2 will be completed in two stroke units by month 20, utlising a full EBCD cycle in order to co-produce, implement and evaluate interventions. The co-produced interventions will aim to increase the nature and amount of supervised and independent therapeutic patient activity. We propose to evaluate changes in behavioural mapping data and experiences of implementing the co-produced

interventions from qualitative findings. If a positive change in supervised and independent therapeutic patient activity following implementation of co-produced interventions, evidenced in either behavioural mapping data or qualitative data from post implementation interviews and feedback events, is found then we will then proceed to test the interventions in two further stroke units in phase 3.

Phase 3 Months 23-32: The same pre and post intervention measures in phase 2 will be used to evaluate feasibility and impact in these further units. Co-design groups will be recruited (majority not trained in EBCD) in the two new sites in order to share the trigger points and interventions developed in phase 2. The groups will be supported to contextualise and adapt the interventions as required before implementation. Baseline data will be collected for a further independent sample of patients. Once the interventions have been implemented and used for more than four months, post implementation data will be collected using methods identical to those in phase 2. The parallel process evaluation will continue through phase 3. Followed by a celebratory event for phase 3.

Process Evaluation – all sites months 3-32
As part of the parallel process evaluation of the impact of the co-produced interventions and participation in that process, semi-structured interviews will be carried out with staff, patients and carers who were directly involved in co-producing the interventions to explore their experiences. In addition, up to ten members of staff/patients and carers in each for the four units (or two units in phase 2 if phase 3 is not undertaken) will be invited to participate in semi-structured interviews to explore their experiences of stroke units during the time the coproduced interventions were implemented and based on the questions proposed by the developers of the NPT approach (May, 2010).

Data Analysis:
Behavioural mapping: We will compare and report on the frequency of occurrence of activity using an approach used by Askim et al (2014), but will also include frequency of occurrence of additional categories in social and cognitive activity. We will compare and report on average and most frequently occurring activity levels recorded on the different days of the week on which behavioural mapping was undertaken. We will also access data from SSNAP to summarise and compare demographic data, age, gender, stroke severity (NIHSS and MRS) from a cohort of 30 patients pre/post implementation in each unit.

PREM and PROM data: We will evaluate experiences, and perceived outcomes in stroke patients using validated stroke PROM/PREM self-report tools. Using descriptive statistics we will summarise and report on these data and then consider them in conjunction with the findings from observations, behavioral mapping and interview data. These data will be used to determine if these measures are feasible to use and can capture changes in experience and perceived outcome in patients who have received care in an acute stroke healthcare setting before and after interventions were introduced to increase supervised and independent therapeutic activity.
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Process Evaluation data: Thematic analysis of the qualitative data (observations and

interviews) from the process evaluation will be used to describe and explain the contextual, interactive, professional and political processes which shaped the nature and organisation of stroke unit work prior to and during the implementation and assimilation of the intervention(s) into routine stroke unit practice, including, for example, the roles of key actors/teams (Eisenhardt, 1989). Analysis will include within and between unit comparisons and utilise the NPT approach to examine intervention development, implementation and assimilation in study sites. These data are critical in understanding barriers and facilitators to subsequent knowledge transfer in stroke services and beyond.

Dissemination and Project outputs:
A range of dissemination approaches will be used to target different audiences for the research, starting with dissemination of the findings of our rapid evidence synthesis. We will produce a final research report for the NIHR journals library detailing all the work undertaken and including supporting technical appendices, an abstract and an executive summary focused on results/findings and suitable for use separately from the report as a briefing for NHS managers. We will also prepare for the NIHR a set of 10 PowerPoint slides which present the main findings from the research and will be designed for use by the research team or others in disseminating the research findings to the NHS. The slides will be made available alongside the report on the HS&DR programme website. The findings will have relevance for policy makers, commissioners and clinicians working in stroke care, elderly care services and those living with long term conditions.

Patients, carers and organisations representing their views, for example The Stroke Association and Patients Association will be interested in use of co-production in acute healthcare settings and its effectiveness in facilitating sustainable patient focused change. Research outputs will be tailored for different stakeholders through formal reporting and presentation to National Clinical Directors (Rudd, Bateman and Young) at NHS England, and within organisations which set standards and guidelines. These include the Intercollegiate Stroke Working Party (ICSWP) and National Institute of Health and Clinical Excellence. The applicants are well placed to maximise dissemination. GC is Clinical Lead (Stroke) for the South London Cardiac and Stroke Network, he and CMcK are members the ICSWP who are aware of this proposal and will review the findings. GR, an expert in the EBCD approach, advises researchers and clinicians internationally.

Findings would inform the King's Fund's online EBCD toolkit and be used as part of the NHS England-funded 'train the trainers' EBCD course'. Our project advisory group includes commissioners, senior clinical managers, patients and carers who will assist in developing materials to maximise dissemination. We would meet with local Cardiac and Stroke Network leads and colleagues in Academic Health Science Networks in London and Yorkshire to optimise translation of evidence into practice. Executive summaries of the findings will be provided to participating stroke units and to patients and carers involved. Existing stroke Consumer Research Advisory Groups in London and Yorkshire will contribute to the dissemination strategy, presenting finding at their meetings and annual conferences (Yorkshire and Birmingham).

Project management:
The lead applicant is Professor Fiona Jones who will have responsibility for delivery of the project and final report on time and to budget. Project site management will be shared jointly between Professor Jones (FJ-London sites) and Dr David Clarke (DC-Yorkshire sites). A core senior project group will meet monthly making use of Skype and teleconferencing comprising co-applicants and inviting other researcher staff as required.

The individual components of the project and the research staff will be managed at each site by FJ and DC and the core team. Professor Glenn Robert (GR) and Professor Alastair Macdonald (AMc) will provide input into the development and implementation of the EBCD co-produced intervention; Dr Geoff Cloud (GC) will provide clinical input and advice from a local and national stroke perspective; Professor Ruth Harris (RH) support with rapid review, qualitative data analysis and report writing. Professor McKevitt will oversee and contribute to analysis of observational and other qualitative components in each phase.

There will be one full-time post-doctoral researcher based in each site London (Kingston and St George's), and Yorkshire for the duration of the project. They will have responsibility managing and contributing to day to day fieldwork, data collection and analysis in London/Yorkshire and co-ordinating patient and carer feedback events, and co-design groups within their respective sites. In order to successfully engage staff, patient and carers in developing, implementing and evaluating the co-produced the interventions we consider it necessary to ensure there is adequate time allocated for FJ, DC and research staff. FJ and DC will direct the work of the research staff and communication with the stroke units through weekly or bi-weekly meetings. FJ and DC will also be allocated time with their 0.2WTE to contribute to rapid evidence review, observational work, interviews, behavioural mapping analysis and the co-design process.

Approval by ethics committees
Our proposal requires full ethical approval as it involves, staff, patients and families recruited through the NHS. The research will also require R&D approval in the relevant trusts, commencing with the first two trusts in London and Yorkshire. Phase 2 ethics and R&D applications will commence as soon as we hear if we are successful. We will submit two further R&D approval applications for phase 3 as soon as we have completed our break point and decided to continue. These applications will start preparation before this time point so as to expedite phase 3.

Patient and Public involvement
Stroke survivors were involved in developing this application. The research outline was discussed at the Consumer Research Advisory Group (CRAG) in July and September 2013. CRAG has links with the Cardiac and Stroke Network in Yorkshire and has been established ten years; members include stroke survivors and carers, some with national advisory roles. The outline was also presented in round-table discussions with stroke survivors and carers at the YSRN consumer conference in October 2013. CRAG members and conference participants strongly supported the proposed research. Most

expressed a view that active inpatient rehabilitation was central to recovery after stroke but felt they did not receive the amount of therapy identified in the national standard. Carers indicated they wanted to help with rehabilitation but did not know how, and did not receive training from staff in this area. Two stroke survivors participated in the research proposal writing group, attending meetings in Yorkshire and London. Their comments helped the research team appreciate how the collaborative research process proposed may be viewed and engaged with by stroke survivors.

Active patient and carer involvement is a feature of every stage of the chosen co-production approach. This study will enable patients and their carers to work in close partnership with frontline healthcare professionals to develop, pilot and evaluate innovations in the delivery of rehabilitation therapy in acute settings. We have a stroke survivors and family member on our study steering committee. These individuals already have experience of participating in stroke research meetings. Stroke survivors and carers will participate, in review of participant information sheets, in discussion with researchers about conducting observations and interviews with patients and staff, and with researchers in the EBCD feedback events. They will also be supported to participate in disseminating findings and recommendations to service user groups, the UK Stroke Assembly and UK Stroke Forum.

Study Steering Committee A Study Steering Committee will meet 4 times face to face during the study. Extra virtual meetings through teleconference or Skype will be scheduled as required. We will ensure that we report, and have regular guidance from members of the SSC at least once every six months, which we think is necessary given the timeline and staged approach to the study design.

Our chair will have experience of setting up and delivering on large scale research projects and previous experience with the use of NPT and Implementation Science. Members will also include academics with experience of implementation and stroke research, senior clinicians and managers who have experience of working in acute stroke care and strategic oversight of organizational aspect of delivery. PPI members involved with the project development have also been invited to be part of the SSC.

A statistician and health economist (RG/DM) are retained on the SSC despite the changes to our study. They are both fully committed to this project and will provide an alternative perspective which will help with explaining to stakeholders about the potential impact on clinical outcomes and cost savings.

Project team:

FJ and DC will be at 20% FTE and will lead the research in London (FJ) and Yorkshire (DC), They will each be supported by post-doctoral 1WTE who will manage and contribute day to day data collection but also assist with each stage of the co-design process. Each co-applicant will have a responsibility for specific components of the project. GC will facilitate access to stroke units and will provide clinical input and advice from a local and national stroke perspective; CMC and DC will advise on qualitative and

process evaluation components; GR will oversee the process of EBCD throughout each phase and ensure workshops and co-design groups are facilitated in accordance with the established tenets of the approach. AM will contribute his time to supporting co-design of interventions particularly in terms of bringing ‘designerly thinking’ to the identification and piloting of potential interventions

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