Using co-production to increase activity in acute stroke units: the CREATE mixed-methods study

Fiona Jones,[1*] Karolina Gombert-Waldron,[1] Stephanie Honey,[2] Geoffrey Cloud,[3] Ruth Harris,[4] Alastair Macdonald,[5] Chris McKevitt,[6] Glenn Robert[4] and David Clarke[2]

[1]Centre for Health and Social Care Research, Faculty of Health, Social Care and Education, Kingston University and St George's, University of London, London, UK
[2]Leeds Institute of Health Sciences, University of Leeds, Leeds, UK
[3]Alfred Health, Melbourne, VIC, Australia
[4]Department of Adult Nursing, King's College London, London, UK
[5]School of Design, Glasgow School of Art, Glasgow, UK
[6]School of Population Health and Environmental Sciences, Faculty of Life Sciences and Medicine, King's College London, London, UK

*Corresponding author f.jones@sgul.kingston.ac.uk

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Scientific summary

The CREATE mixed-methods study

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Scientific summary

Background

Stroke is the most common form of neurological disability in the UK. Depending on the severity of their stroke, survivors will spend anything from a few days to many months as an inpatient. Rehabilitation is an essential component of multidisciplinary stroke care. The 2016 *National Clinical Guideline for Stroke* (England, Wales and Northern Ireland) [Intercollegiate Stroke Working Party. *National Clinical Guideline for Stroke*. 5th edn. London: Royal College of Physicians; 2016] recommends that every day each patient should receive at least 45 minutes of therapy, as appropriate. Yet a focus on 'delivery of therapy', which is usually provided only on Mondays to Fridays, fails to recognise the need to make rehabilitation the basis of the patient's day, as opposed to an infrequent part of it. Any independent or supervised activity, whether physical, social or cognitive, helps recovery, but observational studies show that stroke patients can be inactive and alone for > 60% of waking hours. These figures have remained unchanged since the 1980s, despite many organisational changes, guidelines and national targets. Boredom and apathy are commonplace, and both can have a negative impact on patient outcomes. Innovative approaches to addressing the longstanding problem of inactivity are now required.

Experience-based co-design has successfully initiated improvements for patients, staff and visitors in other acute settings. Experience-based co-design draws on observational fieldwork and filmed narratives with patients to help trigger different conversations and interactions between patients and staff with the goal of improving health-care services. The approach entails equal roles for staff, patients and families in co-designing the changes they care most about.

Our aim was to evaluate the feasibility and impact of patients, carers and staff collaborating to develop and implement changes to increase supervised and independent therapeutic patient activity on acute stroke units. We focused on supervised or independent social, cognitive and physical activity and used an umbrella term of 'activity' for anything that patients do with or without help, however small, outside individual one-to-one scheduled therapy sessions. We also aimed to understand both the experience of taking part in experience-based co-design and whether or not the interventions developed and implemented during a full experience-based co-design cycle in an initial two units could be transferred to two further units using an accelerated experience-based co-design improvement cycle. The feasibility of an accelerated form of experience-based co-design was demonstrated in an earlier Health Services and Delivery Research study in intensive care units and lung cancer services, but there was no focus on the transferability of co-designed solutions and no evidence of use of accelerated experience-based co-design in stroke services.

Objectives

Our first objective was to complete a rapid evidence synthesis of the evidence on the efficacy and effectiveness of co-production as an approach to quality improvement in acute health-care settings.

We then used full and accelerated cycles of experience-based co-design in four stroke units and studied the impact of the changes made on the quality and amount of activity.

Our evaluation focused on the following questions:

- How do patients and carers experience the use of a co-production approach and what impact does it have on the quality and amount of supervised and independent therapeutic activity in a stroke unit?

- How do staff from acute stroke units experience the use of a co-production approach and what improvements in supervised and independent therapeutic activities does the approach stimulate?
- How feasible is it to adopt experience-based co-design as a form of co-production for improving the quality and intensity of rehabilitation in acute stroke units?
- What role can patients and carers have in improving the implementation of the National Clinical Guidelines recommendations about the quality and intensity of rehabilitation in acute stroke units?
- What are the factors and organisational processes that act as either barriers to or facilitators of successfully implementing, embedding and sustaining co-produced quality improvements in acute care settings, and how can these be addressed and enhanced?

Methods

Design

The intervention was experience-based co-design used in four stroke units. Stroke units at sites 1 and 2 undertook all six components of experience-based co-design with the aim of co-designing improvements that would have an impact on stroke patients' physical, social and cognitive activity. At sites 3 and 4 we used an accelerated experience-based co-design cycle starting from a joint staff, patient and family member event to initiate co-design work prompted by trigger films previously developed at sites 1 and 2.

We used a mixed-methods case comparison approach to our evaluation using interviews, observations, behavioural mapping and self-report surveys (patient-reported outcome measures/patient-reported experience measures) pre and post implementation of experience-based co-design cycles. A thematic analysis of qualitative data was carried out, and findings pre and post implementation of improvements within and between sites were compared. We generated descriptive statistics from behavioural mapping and patient-reported outcome measure/patient-reported experience measure data. An embedded process evaluation drawing on normalisation process theory integrated qualitative data and researcher reflections, analysing barriers to and facilitators of implementation of improvements within and across settings.

Setting

The setting was two stroke units in London and two stroke units in Yorkshire (acute and rehabilitation settings). The 2016 national Acute Organisational Audit report [Royal College of Physicians, Care Quality Improvement Department on behalf of the Intercollegiate Stroke Working Party. *Sentinel Stroke National Audit Programme (SSNAP): Acute Organisational Report*. London: Royal College of Physicians; 2016. URL: www.strokeaudit.org/Documents/National/AcuteOrg/2016/2016-AOANationalReport.aspx (accessed 22 April 2020)] showed that all four units performed within the mid-range across key quality indicators and were subject to the staffing pressures and caseload complexity reported nationally.

Participants

A total of 76 staff, 53 stroke patients and 26 family members (carers) were recruited for the evaluation. Participants and additional staff, patients and family members took part in various stages of the experience-based co-design cycle. Forty-three co-design meetings were held across all sites, involving 23 stroke patients, 21 family carers and 54 staff from across all professions and including rehabilitation and support workers, and volunteers.

Results

Our rapid evidence synthesis revealed three main outcomes: (1) the value of patient and staff involvement in co-design; (2) generation of ideas for changes to processes, practices and clinical environments; and (3) tangible service changes and impacts on patient experiences. Overall, there was a lack of rigorous evaluation of co-production studies in acute health care. Future studies should

consider the clinical and service outcomes and cost-effectiveness of co-production relative to other forms of quality improvement.

The findings of the rapid evidence synthesis informed our approach to implementing experience-based co-design, including recognising the importance of local facilitators, recruiting a broad number of patient and carer co-design group members, and maintaining an emphasis on the relational aspects of the work.

Qualitative findings (interviews and observations) across all units showed that it was feasible to co-design changes to increase activity through joint work in three priority areas: 'space' (environment), 'activity' and 'communication'. Experience-based co-design led to improvements in both its full and its accelerated forms. Sites 1 and 2 together co-produced and implemented more than 40 improvements across the three priority areas over 9 months. Filmed patient narratives from these sites proved powerful triggers for action and were utilised at sites 3 and 4, where a similar number and range of improvements were implemented over an accelerated time period of 6 months.

Changes across sites were broadly similar and included environmental and (unit) organisational changes to enable greater social interaction between staff, patients and families; engagement with the community and voluntary sector to provide singing, art and exercise groups; therapy dogs; and personalising bed spaces to encourage 'home into hospital', using 'something about me boards' for every patient, and introducing photo-hangers and familiar home items to facilitate greater social interaction between patients and staff.

Post-implementation interviews indicated that patients, family members and staff had engaged well with experience-based co-design and reported that substantive changes had occurred. Patients and families perceived positive benefits from participating in the co-design groups, felt that they were equal and valued members and gained satisfaction from seeing improvements implemented. Staff reported that CREATE (Collaborative Rehabilitation in Acute Stroke) had been a positive experience, in contrast to their usual work that left little time for creative thought and relational activities. Staff across all units saw co-design as a way to make positive changes to their working environment that provided more activity opportunities for patients. Staff who had not taken part in experience-based co-design expressed similar perceptions.

Ethnographic observations confirmed the use of new social spaces where patients and families could meet and interact, and more activity opportunities provided by groups and community volunteers. However, we found minimal change in the priority area of 'communication'; staff interactions remained fundamentally task focused, with minimal interaction with patients beyond that required for routine care tasks.

Activity levels measured with behavioural mapping were largely inconsistent, showing a mixed pattern of activity and inactivity in those observed pre or post implementation of co-designed changes. Taking the broad measure of 'activity', there was improvement across all sites, but fewer changes were evident at sites 3 and 4 (accelerated experience-based co-design) than at sites 1 and 2 (full experience-based co-design).

Patient-reported outcome measure/patient-reported experience measure data were inconsistent across sites. Response rates were low, varying from 12% to 38%, but cohorts who returned questionnaires had impairment levels, dependency, and emotional and social limitations congruent with national stroke statistics. Patient-reported experience measure data suggested an increase in patients reporting that they had 'enough things to do in their free time' post implementation of experience-based co-design.

Using normalisation process theory to interpret factors influencing engagement with experience-based co-design and implementation of co-produced improvements, we found that the structured time-limited process of experience-based co-design in both the full and the accelerated forms legitimised and

supported participatory co-production activity. All participants recognised that increased activity needed to be embedded in everyday routines and work in stroke units. Communication between staff and patients that supported activity was most challenging to initiate and sustain.

Conclusions

It has proved feasible to implement experience-based co-design in four stroke units. Doing so resulted in qualitatively positive changes in the unit environments and increased activity opportunities for patients. There was no discernible difference in experiences or outcomes between the full and the accelerated form of experience-based co-design. Staff, patients and families in all sites engaged in similar ways with co-design and developed changes in space, activity and communication. Improvement ideas were successfully transferred and contextualised from sites 1 and 2 to sites 3 and 4. Staff participating in experience-based co-design reported a positive impact on their working environment, and patients and families perceived the process to be positive and constructive. Staff not taking part were able to describe distinct changes to their working environment and more activity opportunities.

The implementation of experience-based co-design and the co-designed changes were influenced by several factors and organisational processes, including long-established ward routines that prioritise care tasks, the need to achieve national audit targets and staff pressures compounded by high turnover and shortages.

Our findings mirror those of other research to increase activity levels on stroke units, which have shown mixed results. However, compared with previous studies, new activities and changes were driven by the perspectives of staff, patients and carers using a recognised quality improvement method.

Implications for health care

The benefit of using co-design to initiate change

We believe that the strength of experience-based co-design in both the full and the accelerated form is the facilitated, structured, participatory and time-limited process. The nature of the co-design 'work' was fundamentally different from usual staff-led – or externally driven – quality improvement initiatives in stroke. The approach prioritised the participation of stroke patients and families in more creative and relational interactions and outputs to improve opportunities for independent and supervised activity. The involvement of patients and carers increased the accountability of staff participants and made it less likely that planned changes would not proceed. Co-design facilitated carers' and volunteers' continued involvement in activities and directly contributed to changes made to the day-to-day working of these stroke units. Co-design also initiated new and ongoing engagement with local people and/or organisations for whom the hospital is a key part of local communities.

The ongoing challenge of (in)activity in stroke units

Culture change in any organisation is challenging, and our project was no different. Although the tangible improvements in space and activity opportunities were visible, many interactions between staff and patients remained largely task driven. Interactions facilitating social exchange, cognitive activity or physical activity remained relatively uncommon.

Across all sites we found concern that 'something must be done' and a willingness for staff, patients and families to work together to make improvements. For this approach to be applied across stroke units, local facilitation by a staff member with protected and allocated time is required. The stakeholder mapping exercise at the start of experience-based co-design was critical. Change requires buy-in and commitment from multiple stakeholders, including senior management, to validate the shift away from focusing on achieving national audit targets to a cultural recognition of the therapeutic value of stroke

unit care. This will take time, but trigger films and the experiences of the participants in the four units in our study could help encourage changes, many of which can be initiated quickly and relatively cheaply.

Early consideration of community/voluntary-sector engagement is also important and was a key learning point from sites 1 and 2, which used the full experience-based co-design cycle. This enabled awareness-raising and interest from a range of local community groups that subsequently added to activity opportunities by providing art, exercise groups, reading and music activities.

Implications for research

The cost-effectiveness of the methods used is unknown. Quality improvement methods, such as the accelerated experience-based co-design used at sites 3 and 4, could be highly cost-effective if improvements can reduce the inactivity of inpatient stroke patients, contribute to an increase in independence in activities of daily living and reduce length of stay. Equally, the participatory approaches used in experience-based co-design can have a positive impact on the morale, meaning and purpose of staff in the face of increasing staff shortages and caseload pressures.

Our rapid evidence synthesis highlighted common barriers encountered in co-production approaches. However, we found little difficulty in recruiting patients and carers and retaining their involvement. This was largely because of the dedicated efforts of our local researchers and the willingness of staff in co-design groups to both engage with and support stroke patients and their families to participate in the process.

Several research questions have emerged from our study:

- Can the CREATE accelerated experience-based co-design approach using stroke-specific trigger films be used in other acute stroke units, and what contextual adaptations would be required to enable an increase in activity opportunities for patients through changing the environment (space), communication (enabling activity) and activity opportunities (more access to voluntary and community groups, activity boxes, etc.)?
- What additionally needs to be done to change the culture of activity on a stroke unit? How can 'enabling activity' become part of the routine work of all staff, including nursing staff?
- What degree of cultural and environmental change is required to bring about a significant improvement in activity, and what are the alternatives to quantitative evaluation approaches such as behavioural mapping?
- How can patients/families and local communities support sustained activity outside scheduled therapy provision?

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