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Synopsis

Establishing collaborative partnerships to improve stroke care in India: a synopsis of IMPROVISE, a multi-site feasibility study

Stephanie Jones[1*] Elizabeth Lightbody[1] Elizabeth Boaden[1] Dominique Cadilhac[2] Andrew Clegg[1] Mark Gabbay[3] Rachel Georgiou[1] Josephine Gibson[1] Maree Hackett[1,4] Ranjit Injety[5] Yogeshwar Kalkonde[6] Richard Lindley[7] Pallab Maulik[8,9,10] Sandy Middleton[11] Jeyaraj Pandian[5] Gordon Prescott[1] Kathryn Radford[12] Caroline Sanders[13] Padma Srivastava[14] Anil Sharma[1] Christopher Sutton[1] PN Sylaja[15] Marion Walker[12] and Caroline Watkins[1]

[1]University of Central Lancashire, Preston, UK
[2]Stroke and Ageing Research, School of Clinical Sciences at Monash Health, Monash University, Melbourne, VIC, Australia
[3]Institute of Population Health Faculty of Health and Life Sciences, University of Liverpool, Liverpool, UK
[4]The George Institute for Global Health, University of New South Wales, Sydney, NSW, Australia
[5]Department of Neurology, Christian Medical College, Ludhiana, India
[6]Sangwari-People's Association for Equity and Health, Ambikapur, India
[7]Sydney Medical School, The University of Sydney, Sydney, NSW, Australia
[8]Faculty of Medicine, The George Institute for Global Health, New Delhi, India
[9]Faculty of Medicine, University of New South Wales, Sydney, NSW, Australia
[10]School of Public Health, Manipal University, Manipal, India
[11]Nursing Research Institute, Australian Catholic University, Sydney, NSW, Australia
[12]School of Medicine, University of Nottingham, Nottingham, UK
[13]School of Health Sciences, The University of Manchester, Manchester, UK
[14]Department of Neurology, Paras Hospital, Gurgaon, India.
[15]Department of Neurology, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Thiruvananthapuram, India

*Corresponding author Sjones10@uclan.ac.uk

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Abstract

Background: Globally, five and a half-million people die from stroke each year and 13% of all stroke deaths occur in India.

The programme had two main projects IMPROVIng StrokE care in India (IMPROVISE) and IMPROVIng Stroke care in India – Advancing The INSTRuCT Operations and Network (IMPROVIS-ATION), delivered through six workstreams. IMPROVISE aimed to explore the feasibility and acceptability of implementing three evidence-based care bundles into practice. IMPROVIS-ATION aimed to explore the feasibility of implementing care bundle 1 in four additional hospital sites; the provision of post-discharge care in seven hospitals; and the feasibility of establishing a multicentre ethics approval process within the Indian Stroke Clinical Trial (INSTRuCT) network.

IMPROVISE methods: A multi-centre, feasibility study and nested process evaluation. Three care bundles were implemented sequentially at three hospitals. Care bundle 1: a Global Evaluation of Swallowing and a hydration 'Osmolarity App'. Care bundle 2: a Standardised Neurological OBservation Schedule for Stroke. Care

AQ1
AQ2

bundle 3: post-discharge patient/carer education in the form of animations. Process and outcomes were evaluated in each of four cohorts admitted between July 2019 and November 2021.
IMPROVIS-ATION methods: Semi-structured interviews (all work packages) and focus groups (work package 3) with purposive samples of health professionals, patients and carers (work packages 1 and 2), ethics committee members and principal investigators (work package 3).
IMPROVISE findings: Of 707 patients screened, 515 were eligible and 379 (73.6%) were recruited to the study; 118 (31.1%) female, mean age 59 years (12.8 SD). Overall median National Institute Health Stroke Scale was 9 (interquartile range 5–16); 285 (75.5%) of participants had a modified Rankin Scale ≥ 3.
Global Evaluation of Swallowing swallow evaluations increased to 51 (56.0%) and calculated osmolarity was recorded in 67 (75.3%) in care bundle 1, maintained in care bundles 2 and 3. Standardised Neurological OBservation Schedule for Stroke was recorded at similar levels and maintained to care bundle 3. Four animations were provided in hospital to all relevant carers and patients. The process evaluation found that care bundle implementation resulted in improved decision-making, new roles and responsibilities. Barriers to implementation were patient/caregiver literacy, physical and workforce resources and organisational culture.
IMPROVIS-ATION findings: Work package 1: 16 clinical staff and 12 patient/carers reported variation in practice arising from a lack of specialists and resources. Work package 2: 66 clinical staff and 102 patient/carers identified unmet needs related to swallowing problems and the psychological impact of stroke. Work package 3 (multiple stakeholders): 12 interviews and 2 focus group participants (n = 18) identified some streamlining of ethical approvals following the COVID-19 pandemic, but sustainable standardised procedures were needed for multicentre studies.
Conclusion: Evidence-based, context-specific interventions to improve the basic elements of stroke care can be successfully implemented and sustained as an acceptable model of care.
Future work: Future work is planned to explore the needs of patients and their carers to identify and develop low-cost rehabilitation services.
Limitations: The impact of COVID on hospital systems and processes of care is likely to have influenced the results of the study, including fewer patients recruited than planned, the admission of more severe stroke patients, delays in patients being admitted Stroke Units and the rotation of trained staff to other hospital departments.
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Background

Each year there are approximately 12.2 million incident cases of stroke, 143 million disability-adjusted life-years (DALYs) lost, and 6.6 million premature deaths.[2] Globally, stroke is the second most common cause of death and the leading cause of acquired adult disability[3] and one in four adults will have a stroke in their lifetime (World Stroke Organisation). Almost 70% of all strokes and 87% of stroke deaths occur in low- to middle-income countries (LMICs).[4] Despite a global decline in the age-standardised stroke death rate, the decline has been slower in low-income countries (LICs) and lower- to middle-income countries (21–23%) when compared to middle-income countries and high-income countries (HICs; 38–52%).[5–7] Population level studies from LMICs report high prevalence of stroke and any future increases in stroke rates will most likely be driven by LMICs.[8,9]

India is one of the three countries with the greatest number of recorded stroke deaths worldwide. People in India typically suffer a first stroke at a much younger age than in the UK [India, age 57; UK, age 72 (male) and age 78 (female)],[8,9] leading to significant socio-economic burden.[10]

In the last 20 years, the UK, along with other higher-income countries, has achieved significant improvements in stroke outcomes, including reduced mortality and morbidity. Much of this improvement has been through the introduction of organised Stroke Unit Care. Stroke Unit Care has great potential to reduce mortality and morbidity worldwide, as it is the most widely applicable and effective intervention.[11]

Stroke Unit Care has great potential to reduce death and disability worldwide as the most widely applicable and

effective intervention.[12] To achieve the best possible recovery and outcomes for patients, evidence-based interventions should be available for all patients.[13] One element of Stroke Unit Care that is thought to be effective is an organised specialist multidisciplinary team (MDT) approach and patient-centred care. It has been demonstrated that better adherence to several processes of care in acute stroke is associated with reduced mortality.

A growing body of evidence supports structured quality improvement interventions in improving processes in stroke care and reducing post-stroke complications. In the Quality in Acute Stroke Care (QASC) trial, there was a 16% absolute reduction in 30-day death and dependency following the implementation (training and support) to improve the management of pyrexia, hyperglycaemia and swallowing.[14]

Post-stroke complications are common and require timely identification of risk factors, symptoms and management. An important component of Stroke Unit Care in HICs is the evaluation of patients' swallowing ability. Dysphagia, occurs in approximately half of acute stroke patients[15] increasing the risk of malnutrition, aspiration pneumonia, and consequently mortality and morbidity.[16]

Dysphagia also increases the risk of dehydration. Dehydration affects two-thirds of stroke patients and is also associated with poor outcomes.[17] Patients who are dehydrated post stroke are more likely to experience complications and research suggests that dehydration in acute stroke is associated with early neurological deterioration (END),[18–20] poor collateral flow,[21] increased END, poor discharge outcomes including mortality.[17,22] Adequate hydration may also reduce the occurrence of dehydration-related complications such as infection, constipation and delirium.[23]

Early neurological deterioration occurs in 5–37% of patients.[24,25] If detected early, through the monitoring and subsequent management of a range of physiological parameters including hyper- and hypotension,[26,27] and body temperature[28] the long-term effects of END may be prevented.

One way of delivering structured interventions is via care bundles (CBs). CBs aim to improve standards of care and patient outcomes by promoting the consistent implementation of a group of effective interventions, which when performed together, may have a better outcome than if performed individually.

IMPROVISE aims

The aims of IMPROVISE were to develop three evidence-based multidisciplinary CBs for the management of acute stroke, explore the feasibility and acceptability (for staff, patients and carers) of delivering them, and describe whether there was any indication that patient outcomes were improved. We also aimed to support research capacity building.

IMPROVISE objectives

Overall programme objectives:

1. to conduct situational analysis, develop and investigate the feasibility of implementing three evidence-based CBs to:
    - 1.1. estimate the proportion of those eligible patients among admissions to acute Stroke Units and estimate recruitment (of all eligible) and attrition rates (of all recruited) for all three evidence-based CBs
    - 1.2. test data collection systems, follow-up protocols and outcome measures
    - 1.3. determine fidelity to the delivery of each of the CBs and overall, on the part of staff and of carers
    - 1.4. through an embedded process evaluation, investigate the acceptability of the CBs by service users, their families, and staff and the barriers and facilitators to implementing the CBs
    - 1.5. estimate the impact of implementing the CBs on participant function, quality of life, mood and carer strain.

The study also had CB-specific objectives.

2. CB1: assessment and management of swallowing problems and hydration:
    - 2.1. to estimate the changes (between pre-implementation and after CB) in the proportion of people with the following characteristics:
        - dehydration (as measured by osmolality > 295 mOsm/kg at day 2)
        - staff responses to dysphagia
        - nil by mouth
        - nasogastric tube at discharge.
    - 2.2. to estimate the distribution of time from:
        - symptom onset to stroke admission
        - stroke diagnosis to stroke treatment
        - stroke admission to dysphagia screen.
    - 2.3. to establish the accuracy of point of care (POC) tests for dehydration, individually and in combination with each other, with respect to reference standard laboratory tests for dehydration.

3. CB2: monitoring and management of neurological and physiological signs

    3.1. to estimate the changes in proportion of people with:
    - END (measured by SNOBSS) by day 3.

4. CB3: the education and training of relatives in acute stroke

    4.1. to investigate the impact of the CB interventions on carer outcomes: depression, anxiety, and carer strain.

Methods IMPROVISE

Design

A multi-centre, mixed methods feasibility study with nested process evaluation. An overview of the study design is presented in *Figure 1*. A sample of stroke patients were enrolled into the study at four different time points. To establish baseline practice, the first sample (S_1) were recruited prior to the implementation of any intervention at each site. In the 2-month period which followed, the first CB (CB1) was implemented at all three sites. Once implemented, and prior to the implementation of the second CB2, a second sample of stroke patients (S_2) were recruited to the study. This process continued until all three CBs had been implemented at each site and followed with a 2-month period of data collection. Each enrolled participant and their principal carer were followed up at 90 days and a nested qualitative process evaluation took place alongside the implementation of the CBs at each hospital site. The process evaluation focussed on acceptability of the CBs, barriers and enablers to implementation and to understand how context influenced implementation.

Settings

The study took place in acute Stroke Units in three hospitals in India [All India Institute of Medical Sciences (AIIMS), New Delhi (government hospital with 75 neurology beds including neurointensive care); Christian Medical College and Hospital (CMC) (private hospital with 29 neurology beds including 9 providing neurointensive care), Ludhiana, Punjab; and Sree Chitra Tirunal Institute of Medical Sciences (SCTIMST), Thiruvananthapuram, Kerala (government with 44 neurology beds including 12 providing neurointensive care)].

Participants

Consecutively admitted stroke patients were eligible for inclusion in the study if they:

- were aged ≥ 18 years
- had a clinical diagnosis of acute stroke (i.e. ischaemic stroke or primary intracerebral haemorrhage with a persistent neurological deficit on presentation)
- had been admitted within 2 weeks of stroke onset
- had neurological deficit on presentation.

Patients were not eligible for inclusion in the study if they:

- had a planned discharge from the emergency department without going to the Stroke Unit
- had experienced a transient ischaemic attack (TIA)
- were unable to be followed up at 90 days (± 7 days)
- have no legally acceptable representative to consent on their behalf.

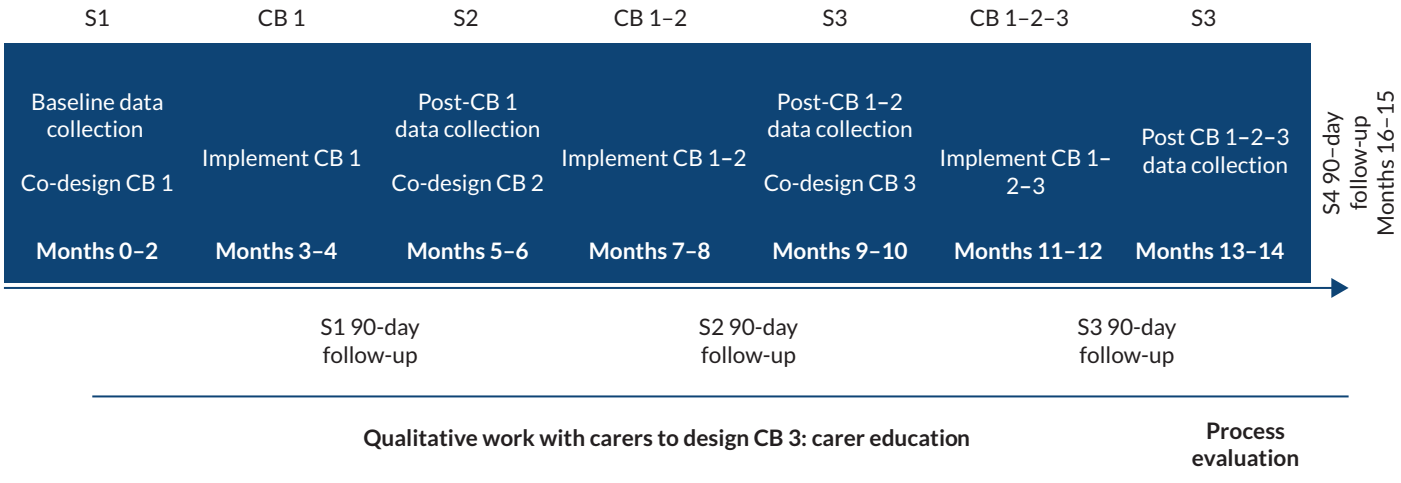

FIGURE 1 Study design.

All carers of study participants were eligible to participate in the 90-day follow-up data collection and process evaluation if they were: (1) aged ≥ 18 years, (2) a relative of the study participant and (3) the principal caregiver for the person who has had the stroke when they returned home.

Clinical staff were eligible to participate in the nested qualitative process evaluation if they: (1) were medical, nursing, or therapy staff; (2) had been actively involved in implementing the intervention and (3) had participated in training related to the intervention.

CB development

Reflecting stakeholder priorities determined through a series of discussion groups with clinical staff patients and carers, the intervention consisted of three newly developed CBs: (1) swallowing and hydration; (2) neurological deterioration and (3) post-discharge carer education and training. Experience-based co-design methods were used to inform the components within the CBs (*Report Supplementary Material 1* for CB content).

Care bundle 1 comprised the Global Evaluation of Swallowing (GEoS) (*Report Supplementary Material 2*), and hydration screening (hydration point-of-care tests and a bespoke Osmolarity App). The GEoS enabled regionally specific foods to be used as testing materials and was translated into Hindi, Malayalam and Punjabi. In CB1, nursing staff and speech and language therapists (SLTs) in one site (SCTIMST) were required to replace swallow screens or previously used swallow evaluations with the GEoS. Serum osmolarity was calculated from routinely collected point-of-care test data (sodium, potassium, urea, glucose and calculated osmolarity) using an 'Osmolarity App' tailored to the Indian context and based on the Khajuria and Krahn formula,[29] which has shown to be a reliable, cost-effective and minimally invasive predictor of directly measured serum osmolality in older adults.[30]

Care bundle 2 utilised the Standardised Nursing Observations Schedule for Stroke (SNOBSS), a neurological assessment tool derived from the Scandanavian Stroke Scale (SSS). The SNOBSS included items for consciousness, speech, eye movements, arm and leg strength. These items had previously shown good reliability when used as part of the SSS.

In CB3 animations were developed to provide post-discharge education on four identified priority areas: (1) stroke awareness; (2) eating and drinking; (3) hydration and (4) regaining independence (*Report Supplementary Material 3* for links to CB3 animations).

Training and implementation

Care bundles were implemented sequentially at each site (see *Figure 1*). In the first phase, site staff were trained in the CB1 content in face-to-face group sessions. CB1 was implemented for 2 months. In the next phase staff were again trained face-to-face in CB2, this was followed by the implementation of CBs 1 and 2 simultaneously for 3 months. In the third phase staff were trained in CB3, due to the COVID pandemic training took place remotely online, CBs 1, 2 and 3 were then delivered simultaneously for 3 months.

A train-the-trainer approach was used with research staff, senior nurses, and clinical champions at each study site (n = 42). Training was followed by facilitated discussions with the clinical champions regarding the training content and practical elements of delivery. Staff were then required to complete asynchronous online training and three observed competency assessments for CBs 1 and 2 to ensure fidelity. Post training the project team met with trainers on a weekly basis to 'trouble shoot' and ensure the ongoing delivery of training as it was cascaded to clinical teams [nurses and research assistants (RAs) at all sites, also included SLTs at one site (SCTIMST)]. Online refresher training was delivered to staff prior to the delayed implementation of CBs 2 and 3 due to COVID.

Recruitment

Separate cohorts of participants were enrolled into the study at four time points (Baseline and CBs 1, 2 and 3) at each of the three participating hospital Stroke Units. Consecutively admitted stroke patients were eligible if they met the pre-defined inclusion criteria. Potential participants were identified by the principal investigator at each Stroke Unit.

Outcome measures

The number of participants recruited (including proportion eligible and reasons for non-participation); completeness of data for each CB [baseline, days 1–3, day 7 (or discharge if sooner) and 90 days]; retention of recruited participants.

Sample size

The target sample size was 504–540 participants, assuming a 70–75% consent rate from 720 eligible patients. The sample size was selected to be sufficiently large to address the quantitative objectives, and in particular, to assess the accuracy of the combined POC test for dehydration and the 'gold standard' laboratory test for dehydration, so the smaller group of dehydrated or hydrated, making up 40% of the sample, would have at least 10 observations per model parameter.

Care bundle data collection

Data collection included: patient demographics (age, sex, stroke type, stroke severity), previous medical history, time from stroke onset to hospital arrival, hospital arrival to Stroke Unit admission, median Barthel Index (BI) at day 1, modified Rankin Scale (mRS) at day 7.

Results summary

Recruitment took place between July 2019 and November 2021 (CB0: July–October 2019; CB1: December 2019–February 2020; CB2: October 2020–January 2021; CB3: August–November 2021). Of the 707 patients screened, 515 (72.8%) were eligible, of those 380 (73.8%) were recruited. One participant was subsequently withdrawn as they did not have a stroke (*Figure 2*).

Participant characteristics are presented in *Table 1*. Median length of stay was 5 days [interquartile range (IQR) 3–10]. Day 7 mRS was recorded for 375 (98.9%) participants and 285 (76.0%) has a mRS ≥ 3. Three hundred and sixty-eight carers were also recruited.

CB1: swallowing and hydration

Following baseline data collection, the GEoS evaluation of swallowing was implemented in CB1. Swallow screens decreased from 30 (32.6%) at baseline to 14 (15.4) in CB1, 1 (1.0%) in CB2 and 8 (8.5%) in CB3. While GEoS was performed in 51 (56.0%) participants in CB1, 62 (60.8%) in CB2 and 52 (55.3%) in CB3.

Calculated osmolarity was recorded in 67 (75.3%) of participants in CB1, 70 (69.3%) in CB2 and 71 (77.2%) in CB3.

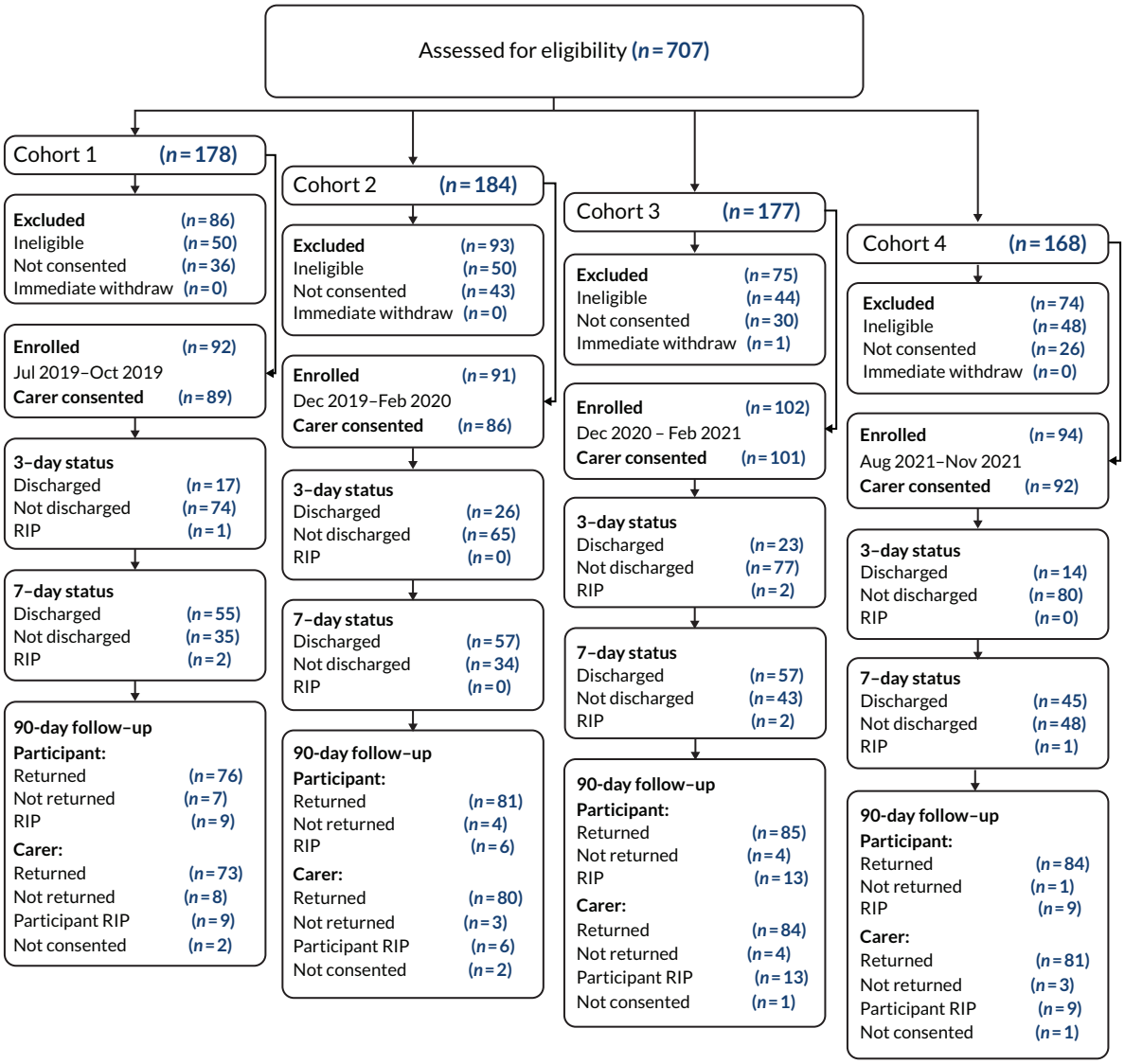

FIGURE 2 CONSORT style diagram.

TABLE 1 Patient characteristics

	Baseline, *N* = 92	CB1, *N* = 91	CB2, *N* = 102	CB3, *N* = 94	All, *N* = 379
Female *n*(%)	26 (28.3)	32 (35.2)	34 (33.3)	26 (27.7)	118 (31.1)
Age mean (SD)[a]	59.9 (11.78)[b]	61.7 (11.93)	58.9 (14.48)	56.8 (12.39)	59.3 (12.82)[b]
Stroke type					
Ischaemic	74 (80.4)	70 (76.9)	72 (70.6)	85 (90.4)	301 (79.4)
PICH	16 (17.4)	21 (23.1)	30 (29.4)	9 (9.6)	76 (20.1)
Not a stroke	2 (2.2)	0 (0.0)	0 (0.0)	0 (0.0)	2 (0.5)
NIHSS recorded *n* (%)	72 (78.3)	74 (81.3)	78 (76.5)	73 (77.7)	297 (78.4)
NIHSS median (IQR)	8 (4.5–14)	7 (4–15)	10 (5–16)	12 (5–19)	9 (5–16)

NIHSS, National Institute Health Stroke Scale; PICH, primary intracerebral cerebral haemorrhage.
a 329 (87%) of ages were estimated by clinicians at site.
b Information not available for 1 participant.

CB2: early neurological deterioration

By day 3, SNOBBS was recorded in 86 (92.5%) of patients levels maintained in CB3.

CB3: post-discharge education

Animations were provided in hospital to all relevant carers and to between 27% and 53% of patients. Following discharge, between 84% and 92% of carers and 69% and 77% of patients accessed the animations.

Follow-up data

Day 90 follow-up data were available for 326 (86.0%) patients, of whom 18 (5.5%) remained in hospital at 90 days. Study 90-day lost to follow-up rates ranged from 10.6% to 11.0% in CB 1 and 3, respectively to 16.7% in CB 2.

Levels of disability varied across the CBs with a mRS ≥ 3 ranging from 35.5% to 67.9%; however, this may reflect differences in stroke severity across the CBs. BI scores were similar across the CBs and indicated a high level of disability. PHQ-9 and GAD-7 scores were similar across the CBs and indicated that the majority of patients had no depression or anxiety.

Discussion

The IMPROVISE study has demonstrated the feasibility of implementing context-specific CBs for the multidisciplinary healthcare team in India, resulting in increased swallowing, hydration and END assessments, and the successful distribution of animations to support stroke patients and their carers after discharge.

Recruitment to the study was feasible; the recruitment rate (74.0%) was higher than other Indian stroke studies, with similar rates of participants lost to follow-up (14.0%). Only 31% of participants were female, likely reflecting cultural bias, with more men seeking health care than women.[31] Rates of type and severity of stroke reflected other published studies; however, higher median NIHSS in CBs 2 and 3 may reflect more severe stroke patients being admitted to hospital during the COVID pandemic.[32–34]

Implementation was supported by a programme of training using interactive and multifaceted methods, including videos, written materials and underpinning competency assessments. Additional training was required throughout the trial for data collection; this may have been due in part to a high turnover of staff and pauses in the trial due to the COVID pandemic. A future trial would benefit from sustainable, resource-efficient models of training.

All three CBs were successfully implemented, and whist challenges were identified, the process was facilitated by tailored training and support. This led to an increase in confidence and helped staff to enhance their practice. In turn this created a sense of optimism among staff who felt that they were able to deliver improved patient care. Previous research in LMICs over a 10-year period identified training and skills as common barriers.[35] Future consideration should be given to how training and skills development could be standardised, assessed and delivered at scale for example, potentially by accessing existing infrastructure and networks.

Scalability of the CBs has been demonstrated through the inclusion of the CBs and associated training in the World

Stroke Organisation (WSO) and National Accreditation Board of Hospitals and Healthcare (NABH) providers joint Stroke Centre certification programme. This programme aims to create the standardised delivery of stroke care across India, promoting quality and safety of care and improving long-term stroke patient outcomes. It is now mandatory for all Stroke Units applying for WSO/NABH accreditation across India to include the IMPROVISE CBs within their Stroke Unit Care.

This main IMPROVISE study has a number of limitations. Participant recruitment was determined by both principal investigator and research staff availability and the final sample size of 379 was lower than the 504–540 intended, with half recruited from one site. Capacity to deliver the CBs was also impacted by staff turnover. The implementation of CBs 2 and 3 was delayed due to the COVID-19 pandemic and the regaining independence animation was disseminated to some participants after discharge due to delays in production. The impact of COVID on hospital systems and processes of care is also likely to have influenced the results of the study including the admission of more severe stroke patients, delays in patients being admitted to the Stroke Unit, as this was dependent on pre-COVID screening and the rotation of trained staff to other hospital departments. There may be variability by site which has not been explored due to the small numbers of participants overall. The three included study sites were established clinical research hospitals; therefore, our findings may be generalisable to similar settings, but these do not represent the range of diverse hospitals in India.

Process evaluation

A nested process evaluation was conducted alongside the IMPROVISE feasibility study.

Process evaluation interviews took place with a purposive sample (profession, patients/care/givers, site, CB) of participants. Staff participants were eligible to take part in they had been actively involved in the CB training and implementation. Patients and carer were eligible in they had been participants in the feasibility study.

One hundred and fifty members of clinical and research staff completed the CB training. Of these, 47 were identified as potentially available for interview following discussion with each site's senior stroke service managers. Others were not approached as they had left the organisation or had been redeployed to other hospital areas. Three hundred and twenty-six participants completed the main IMPROVISE study to follow-up; 65 were identified as suitable to approach for interview.

Data collection

The semi-structured interview guides were informed by existing published research and were developed collaboratively by the research team to explore staff perspectives on the CBs, their implementation, training and supervision received. Patient/caregiver interviews focussed on study processes such as recruitment. Interviews were conducted in English or local language and took place either face-to-face or by telephone shortly after each CB's implementation with staff, and after 90-day follow-up with patients/caregivers.

Data analysis

All interviews were digitally recorded, translated (as required) and transcribed verbatim. Each transcript was read coded to the TDF or COM-B. Twenty-three (52%) interviews were coded independently by two researchers; any discrepancies arising were then discussed by the project team. The remaining interviews were coded independently by individual project team members.

Results

Staff interviews

Of the 47 potential participants who were approached, 27 (57%) agreed to take part [16 nurses, 10 researchers and 1 Speech and Language Therapist (SALT); *Table 1*].

Findings from interview with clinical and research staff interviews mapped to all TDF domains and are presented below with the relevant TDF domains.

New knowledge and skills gained through training, competency assessments and the opportunity to practice was identified as key to successful implementation. Ongoing training and support ensured that the CBs are the associated skills were embedded in practice. IMPROVISE trained nurses in some sites felt empowered as they extended their usual scope of practice.

Research assistants also reported developing research skills but despite this often had to refer consent to the clinical lead when patient and/or their families questioned the RAs position.

Participants were optimistic about the training and support provided; practice changes following implementation and were confident that changes could be sustained.

Barriers to implementation were often due to a lack of resources. The main challenge is difficulties in having the time away from practice to engage in the training. This was largely overcome by offering training by running

multiple training sessions with smaller groups to facilitate attendance. A barrier to participant recruitment was families' awareness/lack of awareness about stroke care and an apprehensiveness or refusal to participate in the study.

Patient and carer interviews

Of the 65 potential participants who were approached, 18 (28%) agreed to take part including 6 patients, 11 caregiver and 1 patient/caregiver dyad. The findings from the patient and caregiver interviews mapped to all domains in the COM-B.

Participants felt that they had gained new knowledge from participating in the study including an increased knowledge and awareness of the symptoms of stroke and stroke care, enabling carers to provide post-discharge care where necessary. Feedback about taking part in the study was positive, with participants suggesting that they would pass on what they had learned to the wider community. The motivation for taking part was largely altruistic, with participants wanting to improve stroke services for other stroke patients and their carers in the future. Although the decision to take part was made easier when there was clear, informative study information in a variety of formats. Taking part also provided a rare opportunity for participants to have their voices and experiences heard.

Discussion

This process evaluation provides important information specific to a contextualised understanding of the implementation of three CBs in a LMIC. The findings provide important insights into how the coproduced, context-specific CBs can be implemented in practice and highlight factors that should be considered for any wider implementation in the future.

In the process evaluation, participants who agreed to participate may have been positively biased towards the study. However, our purposive sampling by profession, site, CB, patient/carer and may increase the validity of the findings. Finally, senior stroke service managers at each site were often the 'gate keepers' to staff participation and may have influenced recruitment, although the extent of any influence is not known.

IMPROVIS-ATION

IMPROVIS-ATION built on IMPROVISE to explore and gain an understanding of how stroke services are set up and operate to identify how to implement a hydration and swallowing CB through interviews and discussions across four hospitals.

During exploration within IMPROVISE of how best to support patients and families to engage in in-hospital care, the issue of psychosocial support post discharge was raised; there is little available. Our co-applicants' ATTEND Trial also found that the trial Rehabilitation Therapists were hampered in their efforts to provide rehabilitation support because patients and families wanted instead to focus on psychosocial issues.[36] Although there is a paucity of data on the long-term consequences of stroke on families in India, anecdotal evidence indicates a significant burden, particularly in rural areas, and in less educated families.[37]

In IMPROVIS-ATION we explored through interviews the potential for providing post-discharge support psychosocial support as well as hydration and swallowing. This could improve patient complications and reduce psychological distress for both patients and relatives, reducing morbidity and mortality.

During IMPROVISE it was identified that a streamlined ethical approvals process could help to facilitate stroke research studies. Indian research ethics requires individual approval from each site, with Health Ministry Screening Committee (HMSC) approval finally conferred only after all site approvals are gained. Preliminary discussions with members of Indian Stroke Clinical Trial Network (INSTRuCT) the Forum for Ethics Research Committees in India (FERCI) and the Indian Council for Medical Research (ICMR) suggested that there was the potential for a multi-centre ethics process which would facilitate stroke and other multi-site clinical research studies in the future. We aimed to map current ethical review process, identify challenges, enablers and the feasibility of establishing a streamlined multi-centre ethics approval process for stroke studies within the INSTRuCT network.

IMPROVIS-ATION aims and objectives

Work package 1 (WP 1) aim: To explore and gain an understanding of how stroke services are set up and operate, to identify how to implement a hydration and swallowing CB.

WP 1 objectives:

- to explore with stroke patients, families and staff the management of hydration and swallowing
- to understand challenges and solutions to the implementation of a hydration and swallowing management CB
- to understand regional differences
- to identify the key components for a potential implementation strategy.

Work package 2 (WP 2) aim: Through interviews and focus groups to map resources for hydration and swallowing problems and psychosocial support following discharge and identify the key components of potential interventions post discharge.

WP 2 objectives:

- to explore patient post-discharge pathways
- to understand patients' and relatives' concerns, contextual challenges and solutions
- to understand regional differences.

Work package 3 (WP 3) aims: With key stakeholders, to map out the current ethics approval process, identify challenges, enablers and the feasibility of establishing a streamlined multi-centre ethics approval process for stroke studies within the Indian Stroke Clinical Trial (INSTRuCT) network.

WP 3 objectives:

- to understand challenges
- to identify enhanced processes for ethical approval.

Design

An exploratory study using qualitative research methods.

WPs 1 and 2 study setting

Five hospital sites across India:

1. All India Institute of Medical Sciences, Bhopal
2. Baptist Christian Hospital, Tezpur
3. Indira Gandhi Medical College and Hospital, Shimla
4. National Institute of Mental Health and Neurosciences, Bangalore
5. Zydus Hospital, Ahmedabad

WPs 1 and 2 subjects

Eligible for inclusion in the study were adult patients (aged ≥ 18 years) with experience of stroke or TIA and their carers. Patients were excluded if they were unable to consent or had no legally acceptable representative to consent on their behalf. Clinical staff (medical, nursing and therapy) were also invited to participate.

WPs 1 and 2 data collection

Demographic (age; sex; occupation) and stroke detail [type of stroke; severity of stroke(mild/moderate/severe); experience of swallowing difficulties (current/recent/previous); psychosocial difficulties (WP 2 only); time since stroke; any disability (MRS)] were collected for all recruited participants from the patient and/or relative. Details of relationship to the patient and age were collected for recruited relatives. Job role, grade and place of work were collected for all recruited staff members in the consent form.

WP 3 setting

The INSTRuCT network relevant organisations, members of the Forum for Ethics Review Committees in India (FERCI) and the Indian Council of Medical Research (ICMR).

WP 3 participant subjects

Key stakeholders were invited to participate in focus groups and interviews as follows:

- employed by an appropriate INSTRuCT site
- from relevant organisations including FERCI and ICMR
- actively involved in developing multi-centre research ethics processes.

WP 3 data collection

Semi-structured interviews and focus groups were conducted with a purposive sample of participants.

IMPROVIS-ATION analysis

Interviews and focus groups were digitally recorded, translated (as required) and transcribed verbatim. All transcriptions were verified by RAs prior to analysis. Data collection continued until saturation, determined as no new information provided from across the participants recruited. Each transcript was read in full, and data explored using inductive coding and analysed using a reflexive thematic method. For WPs 1 and 2, 30 interviews were coded as a group and 36 by individual project members. For WP 3 all transcriptions were coded as a group. Confirmative and contradictory results were discussed by the project team for consensus. Data were analysed thematically using NVivo software (version 1.5.2.) (QSR International, Warrington, UK).

IMPROVIS-ATION WPs 1 and 2 results summary

Sixty-six HCPs participated, 39 (59.0%) were female (*Table 2*).

Three themes were identified:

1. Integrated inpatient discharge care planning processes (five sub-themes):
   1.1. Healthcare system and resources
   1.2. Staff identification and expectations of carers
   1.3. Task-shifting
   1.4. Patient and caregiver training
   1.5. Education and support in preparation for discharge

TABLE 2 Healthcare professional demographics

Healthcare professionals	*N* (%)
Nurses	**23 (35.0)**
Staff nurses	14 (21.0)
Senior nurse officers	7 (11.0)
Intensive care nurse	1 (1.5)
Palliative care nurse	1 (1.5)
Doctors	**16 (24)**
Neurologists	10 (15.0)
Physicians	6 (9.0)
PTs	10 (15.0)
SLTs	5 (8.0)
OTs	4 (6.0)
Dieticians	4 (6.0)
Psychiatrists	2 (3.0)
SWs	2 (3.0)

OTs, occupational therapists; PTs, physiotherapists; SWs, social workers.

2. Post-discharge patient and caregiver roles and challenges (three sub-themes):
   2.1. Patient and caregiver characteristics
   2.2. Caregiver roles
   2.3. Caregiver challenges
3. Patient and caregiver engagement post discharge (two sub-themes):
   3.1. Post-discharge support – hospital
   3.2. Post-discharge support – community-based

Theme 1: integrated discharge care planning processes

Discharge planning processes were integrated throughout the patient pathway, often beginning soon after admission although this varied across sites. Discharge planning frequently depended on the availability of specialist staff, resources and facilities and often resulted in task-shifting.

Sub-theme 1.1: Healthcare system and resources

All sites had localised, inpatient discharge planning processes or protocols in place, but this was largely undocumented.

Sub-theme 1.2: Staff identification, and expectations of carers

There was an expectation that carers would primarily support and provide post-discharge care for patients.

Sub-theme 1.3: Task-shifting

Some sites had well-resourced stroke teams but there was often a shortage of dieticians, SWs and therapists (PTs, OTs, SLTs, psychologists) at other sites, where nurses were the main providers of post-discharge information and support. Staff often described task-shifting as integral to their professional roles and responsibilities.

Sub-theme 1.4: Patient and caregiver training

Patient and carer training usually began at admission and continued until discharge including all aspects of care.

Sub-theme 1.5: Education and support in preparation for discharge

To prepare the patient and carer for discharge, training delivered by HCPs was predominantly provided through verbal instruction and explanation. Accessible written information in appropriate languages was viewed as a valuable source of information, enabling information to be passed from the patient or primary caregiver in hospital to the main caregiver at home.

Theme 2: Post-discharge patient and caregiver roles and challenges (3 sub-themes)

The patient's stroke and patients'/carers' levels of literacy were viewed as important factors in the subsequent 'successes' of post-discharge rehabilitation.

Sub-theme 2.1: Patient and caregiver characteristics

Female, family members were often the preferred carer for both male and female patients.

Stroke severity, post-stroke complications, cognitive and communication problems influenced the complexity and challenges of education and training for patients and their carers.

Sub-theme 2.2: Carer roles

Participants described post-discharge stroke care as largely the role of home-based carers (mainly family members).

Sub-theme 2.3: Carer challenges

Hospital staff provided support and education to an identified carer in hospital in preparation for discharge, although these trained carers were not always the primary carer at home. Staff reported that carers encountered a multitude of challenges including: financial constraints; a lack of time to provide care; varying levels of literacy; difficulties transporting the patient to hospital appointments. Challenges were particularly marked among rural populations.

Theme 3: Patient and caregiver engagement post discharge

Provided at discharge, follow-up appointments were individualised and based on the patient's level of disability, comorbidities and available post-discharge support.

Sub-theme 3.1: Post-discharge support: hospital

Staff reported that it was common for patients to have multiple follow-up appointments with their doctor, who was able to provide advice, treatment and referral to other services, as needed. Some patients had challenges in attending follow-up appointments due to distance and travel costs.

Sub-theme 3.2: Post-discharge support: community-based

Outside of hospital-based care, post-discharge support services (such as counselling/psychological support and physiotherapy) were not stroke-specific and were considered by staff to deliver little additional benefit.

Patient and carer interviews

Of the 65 potential participants who were approached, 18 (28%) agreed to take part including 6 patients, 11 carers and 1 patient/carer dyad (*Table 3*).

Capability

Patient and carers identified knowledge as key in recognising the signs and symptoms of stroke but also in underpinning their capability to manage post-stroke complications and disability. Participants felt that they had gained new knowledge from participating in the study.

Opportunity

Patients and carers spoke positively about all aspects of the study. The opportunity to take part in the study had had a positive influence on being able to care for patients given the environmental and social contexts influencing participants in terms of finances, family support, access to health care and pre-existing roles.

Motivation

Motivation for taking part in the study centred around altruism and the hope that the study would improve the lives of stroke patients and carers in the future. Participants also described taking part in an effort to raise awareness of stroke and as an opportunity to have their voices and experiences heard.

During IMPROVISE it was identified that a streamlined ethical approvals process could help to facilitate stroke research studies. This was addressed in WP 3.

WP 3 results summary

Six interviews took place with Ethics Committee representatives (four Member Secretaries, one Chair and one Ethics Committee Convenor), three (50%) female; representing four government teaching hospitals and two private teaching hospitals. Six interviews took place with PIs, one (17%) female; representing four public teaching hospitals, one private teaching hospital and one charitable hospital.

Participants in the first focus group were all experienced PIs (ranging from 2 to 22 years, and a total of 76 years' experience); 2 (33%) participants were female. Participants represented four government teaching hospitals and two private teaching hospitals from across India.

Following the interviews and the first focus group, a second focus group with 11 participants included: 2 existing PI participants, representing 1 government and 1 private teaching hospital in India and in addition, 3 PIs involved in research in India but based in the UK (representing 2 UK Universities), 3 members representing FERCI and ICMR, 3 members of the project team and a facilitator; 8 (72%) of the participants were female.

TABLE 3 Patient and carer recruitment

Sites	Post CB 1	Post CB 2	Post CB 3	Overall
Site 1 CMC		1 patient	2 patients	3
Site 2 AIIMS	1 carer	1 carer	2 carers	4
Site 3 SCTIMST		5 carers, 2 patients	2 carers, 1 patient, 1 patient/carer dyad	11
Overall	1	8	9	18

The results of the interviews and focus groups resulted in five main themes: ICMR regulations, Ethics Committee processes, Ethics Committee member roles and workload, suggested solutions, and the impact of COVID.

ICMR regulations

All recognised Ethics Committees are registered with the ICMR Department of Health Research. Ethics Committee members outlined ICMR regulations that determine the way in which their committees operated (covering adopted processes, membership and training).

Ethics Committee processes

Overall PIs and Ethics Committee members were positive about current ethical review processes; there was variability in how the committees operated in the different organisations. Having reliable access to Ethics Committees was a concern for some PIs, particularly in relation to timings of committee meetings and the potential impact that this may have for any external approvals and potential delays to study set-up.

For Ethics Committee approval at a national level, the sequence of approvals was sometimes unclear to the PIs, particularly the approval required from HMSC. In some instances both HMSC and hospital Ethics Committees were providing provisional approvals dependent on the outcome of the review and requirements were often applied differently across organisations.

Ethics Committee member roles and workload

Ethics Committee members viewed their role as one of facilitating research but undertaking their role alongside other responsibilities was sometimes difficult due to workload pressures. The roles and responsibilities of members did not only cover the ethical considerations for studies but also included a role in monitoring and overseeing studies following approval, progress reports, study monitoring and closure.

Suggested solutions

Ethics Committee members were keen to facilitate approval where possible between meetings, where research studies needed to start urgently. Members were positive towards expedited approvals and for changes to streamline processes.

Participants were positive about any potential moves towards a more centralised review for some types of research (observational, non-drug/device clinical trials) but the consensus was that applications would still need to be approved by their individual institutions or approval provided by a government regulated body.

Participants described the requirements for developing different processes for different types of studies based on potential complexity and risks for example drug trials versus observational studies and different funding sources. Focus group participants agreed that ICMR could potentially give a generalised approval which would then make it easier for organisations to give permission.

Impact of COVID

The impact of COVID changed how Ethics Committee worked, in terms of the methods and frequency in conducting the Ethics Committee meetings and approval processes of studies. The way committees operated had changed due to the COVID pandemic.

This section has presented the findings from IMPROVISATION; a discussion of the findings within the wider context is now considered.

Discussion IMPROVIS-ATION WPs 1 and 2

This study identified a number of strengths including comprehensive individualised treatment planning, task-shifting where there was a lack of specialists, comprehensive patient and caregiver training, and post-discharge care facilitated by hospital, and community-based services, where available. Participants represented a broad range of stroke services; of which, over a third were nurses of varying seniority. Interviews were conducted in local languages to maximise engagement and by providing participants with a choice of interview method (telephonic or face-to-face), this enabled adherence to COVID-protocols and supported inclusion of participants under COVID restrictions at the point of interview. However, there were also some significant challenges.

The results from WPs 1 and 2 found that female family members were usually responsible for all aspects of care and activities of daily living post discharge, as has been reported in previous research.[38] Congruent with other reports, HCPs identified challenges in training and education, and consequently difficulties for carers when stroke survivors had complex care needs.[38]

The preparation of carers is a vital aspect of in-hospital discharge planning, as post-discharge care is frequently the responsibility of family members in LMICs.[39] However, patient and carer characteristics (demographic, socio-economic and stroke severity) and social roles (employment status, family structure and dynamics), all had an impact

on the subsequent accessibility, availability and provision of post-discharge care, as has been reported elsewhere.[40]

Post-discharge support beyond hospital settings was lacking in the community, as a result alternative medicine, unlicensed practitioners and faith-healers were often sought, particularly among rural populations, common practice in India.[41]

The provision of tailored and individualised information, education and training for patients and carers was often dependant on the availability of both staff and resources. As not all hospitals in the study had comprehensive MDTs, with reported shortages of dieticians, SWs and therapy staff, task shifting was common, particularly within nursing roles. Task-shifting describes a situation where a task is transferred to a HCP with a different or lower level of education and training, or to a person specifically trained to perform limited tasks.[42] Nurses would often take on the roles of other HCPs despite limited training in these additional areas. There is currently no documented evidence of stroke-specific task-shifting training for non-neurologist HCPs, with HCPs reporting that they largely developed knowledge and skills through informal or experiential learning.

Further data and research are needed to understand the support available and needs of stroke survivors and carers, to inform the development of innovative post-stroke interventions that are accessible, patient-centred and culturally sensitive.

Work packages 1 and 2 have a number of limitations. Firstly, the study did not seek to interview HCPs based in the community as these services varied between the included sites and were not stroke-specific. Due to the diversity of the included hospitals, we were unable to make comparisons across services. Hospital staff broadly lacked awareness of the spectrum of stroke care services available in-hospital (outside of their own profession) and in the community. Finally, it is acknowledged that one in every three patients with stroke do not access appropriate health care due to non-affordability, usage of alternative medicines, and difficulty in conveyance to hospital.[40]

Discussion IMPROVIS-ATION WP 3

Work package 3 mapped current ethical review processes and identified the challenges, enablers and feasibility of establishing a streamlined multicentre ethics approval process for stroke studies within the INSTRuCT Network.

This WP identified a number of strengths including streamlining of the current two-stage scientific and ethical review processes into a single Ethics Committee review process and recent requirements for all recognised Ethics Committees to be registered and accredited with the ICMR Department of Health Research, and operating according to ICMR regulations including constitution, tenure and training requirements (e.g. GCP). Participants represented a broad range of organisations (ICMR, FERCI, public teaching hospitals, private teaching hospital and a charitable hospital, and UK universities). By providing participants with a choice of interview method (telephonic or online platforms), this enabled adherence to COVID-protocols, and supported inclusion of participants under COVID restrictions at the point of interview.

In recognition of the potential benefits of international collaborative research, many funding streams actively promote and/or require cooperative efforts.[43] This trend is particularly evident in health research, where collaborations are viewed as essential for addressing global health disparities and to build research capacity in LMICs.[44] However, our study has identified challenges, particularly for PIs in terms of obtaining ethical approvals, often due to variability in how often the committees met, (different organisations met between monthly to quarterly) and the complexity of processes including different approvals needed for internationally funded (multicentre trials in particular), which could lead to delays in research study set-up of up to 2 years.

While different types of research studies in India require additional approvals (e.g. HMSC regulates research projects involving foreign assistance and the DCGI is responsible for the overall approval and monitoring of drug related clinical trials), there was a general consensus that the approvals process could be expedited and/or streamlined depending on study type and funding sources using a range of approaches including expedited review for observational studies, collaboration between Ethics Committees to ensure that consensus could be reached regarding questions, clarifications and amendments needed, and the utilisation of existing research Ethics Committee infrastructure, for example within the INSTRuCT Network. However, these processes would require SOPs formulated by a centralised body for example ICMR or DCGI, where applicable. During the study, ICMR were in the process of piloting a streamlined approvals process, further details about the pilot were unavailable at the time of writing but further information will be available from ICMR in due course.

Ethics approval for collaborative research studies should include ethical approval from both HIC and LMIC institutions whenever possible[43,44] but challenges can arise

from changes being requested to key study documentation following approval by one country or organisation, resulting in amendments to original documentation and the subsequent requirements to submit minor/major amendments, often leading to further delays. The recent change to the combining of scientific and Ethics Committees in India may help to alleviate some of these issues but further lessons must be learned from recent international, multicentre studies and examples of good practice shared between both HIC and LMIC organisations.

While the COVID pandemic resulted in many challenges, it has also highlighted the possibilities of expediting ethical approval for multicentre studies and there are now processes in place and precedent for streamlining processes for multicentre research studies within India.[45] As a result of COVID there had also been a number of changes to Ethics Committee procedures such as online meetings allowing greater flexibility for meetings and ensuring committees have quorate, electronic systems for the submission of ethics applications and virtual committee meetings. However, there was mixed feedback from Ethics Committee members with some preferring to meet face-to face rather than virtually. While others felt that it was easier to clarify questions remotely with PIs rather than waiting for set meeting dates. Despite the differences in opinion there are many changes that occurred as a result of the COVID pandemic that are likely to be sustained and may reduce workload and facilitate timelier streamlined ethical approval processes.

However, it is recognised that the study has a number of limitations. Firstly, the study focussed on including participants from research active organisations, primarily from within the INSTRuCT Network, and, therefore, the findings may not be generalisable to organisations outside of the INSTRuCT Network. The PIs involved in the study were all experienced and are more likely to be familiar with ethics approval processes and procedures for a range of study types. The study took place during the COVID pandemic when major changes within organisations were taking place.

Following presentation of the results and discussion of the findings, achievement of the overall programme objectives will now be discussed.

Achievements per programme objective

The development of a sustainable partnership for stroke research and service development with clinicians, academics, stroke survivors, carers and the public was achieved through close engagement with all partners and co-designing across all stages of the research process. The partnership led to future stroke research that is feasible and acceptable and can provide an evidence base for stroke care in India that has, and will continue to improve stroke services and outcomes for patients.

We developed effective ways of working together to prioritise, develop, deliver and implement research. Our overall aim was to improve stroke care in India by addressing priorities via high quality research. Understanding priorities and agendas informed our project plans and supported impact. The programme was informed throughout by agreed priorities for stroke care identified by clinical staff, stroke patients/carers. We focussed on areas of care that all stroke patients could benefit from and could be readily implemented in low resource settings.

Early milestones focussed on key set-up activities, consolidation of the collaboration, and critically, agreed research priorities using codeveloped criteria. Our intention from the outset and throughout was to engage with key stakeholders to identify different needs and priorities, to ensure interventions were relevant, important, accessible and practically focused. We developed effective ways of working with key stakeholders and built sustainability with the coproduction of site-specific bedside-swallowing and hydration evaluation, END protocols, animations, training and guidelines, to reflect regional differences. We have continued to involve key stakeholders (ICMR, FERCI, World Stroke Organization and the National Accreditation Board of Hospitals and Healthcare providers) and have kept them informed of the outcomes and activities within the programme. For example, following the results of the study we worked with the World Stroke Organization (WSO) NABH providers joint Stroke Centre certification programme. This programme aims to create the standardised delivery of stroke care across India, promoting quality and safety of care and improving long-term stroke patient outcomes. The IMPROVISE CBs and associated training and education are now mandatory requirements within the WSO/NABH Stroke Unit accreditation process across India.

We embedded co-design across all stages of the research process to ensure full involvement with our partners, clinical staff, patients and their carers in selecting the priorities for the programme and informing the research design and outcomes. We successfully conducted co-designed studies of stroke care initiated in acute hospital settings.

We undertook extensive engagement with clinical staff at each site to understand the challenges, priorities, barriers and facilitators to implementation. We held face-to-face

discussion groups in all sites with staff from different professions, varying levels of seniority who informed the development of the CBs (design of documentation, management, action and implementation plans). Following implementation of the CBs in practice we conducted a process evaluation with health professionals, research staff, patients and carers to fully explore the feasibility and challenges to implementation.

The milestones relating to research capacity and capability were achieved through development opportunities that were maximised across the partnership for organisations, collaborators, clinical staff and staff employed to work on the programme. Following a learning need assessment, we established a training programme appropriate to individuals' experience, knowledge, skills and the need to develop key competencies required for successful delivery. Training examples include: stroke training and awareness resources (STARS) training; fundamentals of acute care and treatment after stroke (FACTS); good clinical practice (GCP) training; Montreal Cognitive Assessment (MoCA) training; NIHSS training; research ethics in practice; qualitative research including conducting semi-structured interviews and analysis using NVivo; statistics; and writing for dissemination.

Completed by 25 IMPROVISE/IMPROVISATION RAs and six members of staff. RAs completed a minimum of five practise interviews, with bespoke feedback and supervision. Weekly meetings also provided opportunities to re-cap aspects of the training. Sharing experiences and learning within the group further consolidated new knowledge and skills.

> *A real positive of this project is the involvement of the RAs. the PIs were happy to know that the RAs were learning a lot and the RAs felt part of the project rather than just collecting data*
>
> *Quote from site PI*

Training delivered by Lancashire Clinical Trials Unit included: Practise answers to the case report forms (CRFs); site initiation; consent; registration, screening log/tracker and CRF completion; REDCap data entry; common CRF errors; discussion of all queries from the pre-implementation stage; assisting with completing data entry and resolution of all queries; and modified Rankin Score training.

Training on implementation and delivery of the CBs and associated competency assessments were completed by 144 members of staff across the three IMPROVISE sites.

Fifteen health professionals completed the Essentials of Acute Stroke Practice module delivered by UCLan. Our Programme Manager and Senior Research Administrator (UK) and Research Coordinator (India) each successfully completed PRINCE2 training.

The training, skills and experience gained by the lead site in India has enhanced the capacity of the institution to deliver high quality complex research with the longer-term impact of providing improved stroke care.

Coproduction has ensured sustainability for the ongoing implementation of the initiative. Online staff training/competency assessment ensures that new staff can undertake training and trained staff are able to refresh their knowledge and skills. Staff from other departments have also accessed the online training and implemented CB tools. The training has improved staff confidence and competence across the hospital setting and has improved the quality of care delivered to patients; this has included transferable knowledge to other settings and relevant health conditions. For example, a positive consequence has been the wider use of the GeOS across one hospital site. The outcome of using GeOS was that more patients received a swallowing assessment, more patients were allowed a modified diet and fewer tubes were used for feeding. Increased satisfaction in improved care supported use of GEoS in other specialities across the hospital beyond the Stroke Unit to other patients with swallowing problems due to other conditions such as Parkinson's disease, cancer and head injury.

A further example is due to the success of the CB3 animations; there has been wider distribution of the animations than anticipated, including in non-stroke-specific wards, at some of the IMPROVISATION sites and to other hospitals beyond. Due to the topics covered in the animations, they have also been useful for informing clinical staff, patients/carers with a range of non-stroke-specific conditions and disabilities. At one site, following patient/carer participation and feedback in the programme, a SW was employed with responsibility for providing supporting patients and carers during discharge planning and beyond.

> *Even though we were doing the discharge planning our social worker didn't really get involved … The Research Associates trained the social workers to continue with the discharge planning, so it's still being continued*
>
> *Quote from site PI*

While the programme objective were successfully achieved, there were a number of significant challenges.

Significant changes

The most significant change to the programme was the COVID pandemic which impacted on delivery. Significant adaptations to the programme were needed so that delivery could continue in a revised form. The programme team and LMIC partners constantly re-evaluated and re-planned as the pandemic had different impacts, at different times, in different places. This increased the workload of the programme team and LMIC partners, at a time when staff members were under increased pressure and in some situations, very difficult circumstances including bereavements as a direct result of the pandemic.

COVID-19 resulted in delays to the start of CB2 and reduced participant recruitment (both CBs and the process evaluation). This was due to a number of factors including: local COVID restrictions at hospital sites, local restrictions limiting travel, considerations around staff safety, and once restrictions had lifted, reduced numbers of patients with a stroke being admitted to hospital. Data collection was delayed, commencing in October 2020, completed by April 2021. CB3 was delayed. Due to commence in January 2021, it started in August 2021 due to delays in the development of the animations (also impacted by COVID) and was completed by January 2022. Participant characteristics are also likely to be impacted by the COVID pandemic with higher median NIHSSs in CBs 2 and 3, and higher proportion of patients with PICH, suggesting that milder stroke patients were not accessing hospital during the pandemic. Due to pre-COVID screening measures there were delays in patients being admitted to Stroke Units, resulting in delays to assessments included within CB data collection.

Study implementation was supported by a programme of training using interactive and multifaceted methods, including videos, written materials and competency assessments. Additional training was required throughout the study in relation to data collection; this may have been due in part to a high turnover of staff as they were rotated to other clinical settings to support and pauses in the trial due to the COVID pandemic.

Despite the changes to the programme as a result of COVID there were a number of positive aspects including increased communication across the programme which led to greater levels of engagement as we worked together to develop solutions. Animations replaced potential films, as no face-to-face production of a film(s) was possible. IMPROVIS-ATION was due to start on 1 August 2020 but due to reduced availability and capacity of colleagues to assist with contractual, due diligence and ethics submissions, the IMPROVIS-ATION started on 1 January 2021 and was completed by 30 June 2022. Despite completing due diligence and other processes, one site (AIIMS Bhopal) withdrew from the project due to COVID pressures. The flexibility of NIHR to allow amendments to the project timeline and re-profiling of the budget and general support resulted in the programme delivering all its main aims and objectives.

Key to the successful delivery of the programme objectives was engagement with partners and stakeholders throughout.

Engagement with partners and stakeholders

Throughout we have worked closely to establish, develop and extend a sustainable and equitable partnership, fostering productive research collaborations. Decisions regarding the programme have been made collectively and equitably, with awareness of who is best placed to make the decision. For example, decisions about what would work within local centres and contexts was based on advice from clinical leads. We built an effective partnership early in the programme, established roles and responsibilities, maintained effective and regular avenues of communication, set up programme governance systems integrating regular inclusive meetings to oversee delivery and facilitate timely shared decisions. Having an effective partnership has been essential to ensuring that the programme work has continued throughout the challenges of the COVID pandemic, where frequent discussions and decisions had to be made to enable continuation. We have been able to successfully extend our partnership to include other clinicians and researchers at four other centres and believe there is scope to expand further in the future. The programme is an example of truly multi-disciplinary stroke research which is unusual within India and exemplifies how patient care can be improved through multidisciplinary collaboration.

We also formed a new partnership with the Indian Institute of Technology (IIT) who supported us to develop the animation resources for CB3.

We identified key stakeholders at the initiation of the programme and continued to engage with these through involvement in key initiatives, representation at committees, working groups and boards, and developments for stroke care and stroke research. For example, Prof Jeyaraj Pandian is now an advisor to the non-communicable disease Board of the Indian Council for Medical Research (ICMR). He is involved in discussions relating to the feasibility of setting up a national network for clinical trials of Investigational Medicinal Products and

the development of cross-institutional research capacity initiatives within the north of India. We developed a collaboration with key Stroke Nursing Leaders from across India and held an engagement event in New Delhi in January 2020, delivering a subsequent report on stroke care priorities, barriers and enablers to implementing changes in stroke services, and next steps that included setting up a community of practice. This was discussed with the leads for the Nursing Now campaign.

We have continued to involve members of the ICMR in discussions relating to the programme. ICMR fund the INSTRuCT network led by Prof Pandian and the clinical lead for stroke has been informed of the development of the programme and key findings. We have worked with the President and Vice President of the FERCI to hold discussions relating to the possibility of streamlining multicentre ethics approval processes with key stakeholders including the Head of the ICMR Bioethics Unit. Further developments are ongoing, and partners remains in discussion regarding potential changes for the future.

In conjunction with partners in India we were awarded funding from the Academy of Medical Science to undertake networking activities with several countries in Africa and to support the development of the African Stroke Organisation to inform the Strategic Action Plan for Stroke in Africa: Vision 2030. Networking activities include: a systematic review,[46] 2 surveys across Africa (expert survey – completed by stroke experts representing 45 African countries, covering an estimated 95% of the population and Stroke Unit survey)[47] and a Stroke Leaders' Summit in June 2022 (attended by over 50 participants from the UK, Europe, USA and Africa), which set key objectives to operationalise a roadmap for reducing the burden of stroke in Africa across the four pillars of research, capacity building, improving stroke services and multi-stakeholder collaboration, as set out by the African Stroke Organization.

Stakeholders

We have continued to involve key stakeholders (ICMR, FERCI, and the World Stroke Organization) and have kept them informed of the outcomes and activities within the programme. The UK: Africa Stroke partnership has also worked strategically with a range of partners and stakeholders representing more than 20 organisations including the African Academy of Neurology, Society of Neuroscientists of Africa, H3Africa Consortium, American Heart Association/American Stroke Association, European Stroke Organization and the Asian Pacific Stroke Organization.

As well as engagement with partners and stakeholders, community engagement with patients, carers and the public shaped the activities within both IMPROVISE and IMPROVISATION.

Community engagement/patient, carer and public involvement

We codeveloped and delivered a variety of community engagement and involvement activities over the lifetime of the award. Our approach and strategy was co-designed based on extensive start-up phase discussions with patients and carers. We adapted our approach through reflection, feedback and lessons learned after each activity. At multiple points we reflected on PCPI activities in relation to the PPI NIHR INVOLVE standards.

We undertook a series of PCPI discussions about stroke and its impacts with patients/carers at the IMPROVISE sites: AIIMs (2018): 15 patients and 30 carers participated in 5 discussion groups conducted in Hindi; SCTIMST (2018): 6 stroke patients and 7 carers participated in 2 groups conducted in Malayalam, Hindi and English; and CMC (2019): 6 patients and 8 carers participated in 2 groups conducted in Hindi and Punjabi. These events provided rich insights into individual stories of experience for both patients/carers that were of direct relevance to the development and implementation of the CBs.

The IMPROVISE hospitals (charitable, government and private) with differing patients and set-ups, in different regions of India and our PCPI work in these areas ensured that we adapted the CBs to fit the local context. For example, we adapted the information materials for swallowing management which included information about the types of food a patient could be offered, including examples of local dishes with the correct consistency. We originally planned to have further facilitated PCPI group discussions during the development of the content for the stroke information animations for CB3. This was not feasible due to COVID. However, research and clinical staff at sites actively engaged with patients and carers throughout the process at each iteration.

We undertook extensive engagement with clinical staff at each site to understand the challenges, priorities, barriers and facilitators to implementation. We held two face-to-face discussion groups in all sites with staff from different professions, varying levels of seniority (around eight attendees at each) who informed the development of the CBs (design of documentation, management, action, and implementation plans).

The programme was informed throughout by agreed priorities for stroke care identified by clinical staff, stroke patients and carers. We have focussed on areas of care that all stroke patients could benefit from and could be readily implemented in low resource settings. What we learned has shaped how we co-designed and implemented the CB interventions.

Stroke Community engagement with patients, carers contributed to a number of Sustainable Development Goals; these are outlined below. There are a number of inequalities in stroke patient care and these will be described within the context of equality, diversity and inclusion.

Equality, diversity and inclusion

Our programme addressed challenges in stroke care relating to Sustainable Development Goals: No Poverty (1); Good Health and Wellbeing (3); Quality Education (4); Gender Equality (5) and Reduced Inequalities (10).

Stroke patients are a vulnerable population and stroke is a major cause of death and disability. In our systematic review, we reported that in the seven studies reporting this information, or available from respective population registries, the total number of females who experienced a stroke was 10,196,707 (48%). In the IMPROVISE study of 707 patients screened (230, 32.7% female), 515 were eligible and 379 (73.6%) were recruited to the study, 118 (31.1%) female. Other stroke studies have reported a similar percentage of female patients (33%), significantly lower than that of Western and Chinese populations[48,49] and likely to reflect cultural bias, with men more likely to seek medical care.[31]

Stroke patients and their carers are often excluded from engagement and involvement activities due to difficulties in communication, understanding and practical aspects of attending/contributing to meetings. There is also considerable stigma associated with stroke in India which results in many families limiting social interactions.[50] We codeveloped and delivered a variety of community engagement and involvement activities over the lifetime of the award to ensure equality, diversity and inclusion.

In India, the majority of stroke survivors have disabilities, and the burden of long-term care often falls on female family members. In codeveloping the patient/carer defined CB3, we built on our previous experience of engaging with stroke survivors through the use of different approaches and assistive communication aids to ensure involvement. The information we gathered from our PCPI discussion groups integrated involvement of females/males equally, while taking account of cultural and societal contexts. Consideration was given to the physical and emotional needs of patients and their carers, and steps were taken to ensure that discussion groups could adequately accommodate patient and carer needs including sufficient, space and time, the presence of translators and extra staff to support participants. Consideration of gender mix, language preferences and size of groups was important to achieve a supportive environment for individuals to share their experiences and opinions.

All CBs ensured empowerment, ownership, adaptability and localisation. Examples from CB3 are provided here. Patients and carers determined the priorities and content of the animations developed in CB3. The CB3 animations provide information about stroke care, enabling patients/carers to understand more about how to avoid common complications that occur following stroke and promote recovery. Research/clinical staff at sites actively engaged with patients/carers throughout the animation development process at each iteration, having individual discussions and providing extensive feedback. This ensured that scripts for voiceovers and subtitles could be understood. This was of particular importance when direct translations of words from English to local languages were not available. The ability to provide informed post-discharge care will promote improved outcomes for stroke patients and the burden of care which disproportionally falls to female family members. The animations have been developed in local languages with subtitles to aid the training/education of patients/carers with low levels of literacy, limited resources to afford access to health care and geographical barriers. The content of the animations has been developed to ensure that the key messages can be understood without necessarily being able to hear the audio content or read the subtitles.

CB3: In India, stroke occurs at a much earlier age than in higher-income countries (mean age 52 vs. 78) and is more common in men, who are often the main 'breadwinners'. The burden of caring for stroke survivors often falls to female family members; improved outcomes and empowering carers will reduce this burden. In CB3, we codeveloped four animations [(1) stroke awareness; (2) eating and drinking; (3) hydration; and (4) regaining independence] that were made available to download in six different languages (Punjabi, Hindi, Malayalam, Assamese, Kannada and English) and provide information about what a stroke is, how to prevent a stroke in the future and how to care for someone who has had a stroke. Helping people to recover after stroke will reduce the financial burden of stroke often experienced by stroke patients and their families. Improving access to information about stroke

care will reduce the current differences in the access to, and availability of stroke care information (also found through interviews with staff, patients and their carers in IMPROVISATION WP 2), often due to not being able to afford health care or medicines or living a long distance away from specialist healthcare facilities. The animations provided information/education around post-stroke care that people can easily be understood, and that is appropriate to their background.

In partnership with SCTIMST, we codeveloped and delivered the first international multidisciplinary conference on stroke in India, attracting over 350 healthcare workers from every profession in stroke care. The conference opened discussions about research priorities, as well as engaging with a wide range of practitioners, providing a unique opportunity as there are few inter-professional networks for those interested in stroke care. The conference was highly successful in ensuring equity, inclusivity and relevance while promoting active engagement from attendees.

Research collaborations between HICs and LMIC groups are normally set against a backdrop of inequities. IMPROVISE was one of two of the first UK-funded projects to implement a new ethics code, The Global Code of Conduct for Research in Resource-Poor Settings.[43]

The findings from both IMPROVISE and IMPROVISATION and experiences from the programme overall have provided a number of opportunities in terms of both impact and learning.

Impact and learning

The strengths and limitations of the individual CBs and WPs of this research are considered earlier in this synopsis and in each of the published articles.[1,51] For publications as they become available will can be accessed at UCLAN Global Health Research – IMPROVISE. This next section will discuss the lessons learned in relation to the wider programme.

Recruitment was lower than anticipated, mainly due to challenges during the COVID pandemic. However, further discussions with principal investigators and a more complete understanding of participant recruitment models could have informed recruitment planning and capacity to deliver the CBs at an earlier stage, where possible. When designing future studies, consideration should be hierarchical structures that exist within many LMIC healthcare settings and how these may shape research delivery. Participants that were recruited were representative of stroke patients at the time of the study and there were similar rates of participants lost to follow-up (14.0%) as reported in similar studies in India. There may be variability by site which has not been explored due to the small numbers of participants overall and the results may not be generalisable to other healthcare settings, as the sites which took part in IMPROVISE in particular had established Stroke Units and were experienced in stroke research delivery.

Locally led health research is critical for overcoming global health challenges in LMICs.[52] In our experience, there were challenges in recruiting staff with qualitative research experience and therefore it was important to engage staff who had a willingness to gain experience and develop relevant skills. Subsequently, a training programme was developed to provide staff with opportunities to develop theoretical knowledge related to qualitative research, as well as opportunities to practice and develop their practical skills. Key to this was one-to-one and group training and supervision, time for personal reflection and group discussion. Qualitative research methods training should be considered in capability and capacity building activities to grow future stroke research in LMICs.

In developing research capacity and capability, more sustainable learning resources would have been valuable given the high turnover of staff involved in CB delivery. These should take into account different learning styles and the possibility of accredited learning opportunities.

CEI and patient and public involvement and engagement (PPIE) is an essential for global health research in order to achieve impact and to achieve the ambitions of the SDGs. PPIE activities need to be developed that reflect the local context and account for and adapt to cultural differences both nationally and regionally. Understanding the expectations and prior experience of PPIE is essential to inform plans. Locally based staff who are skilled in engaging with people about research are best placed to conduct PPIE activities and evaluate the impact.

The programme adopted the principles of the global code of conduct for research in resource poor setting;[43] however, local regulations, standards, and practices limited implementation of all the standards outlined. For example, national financial regulations limit the re-imbursement of expenses for contributors. The development of the NIHR standards for public involvement in research provides a useful framework for PPIE planning[53] but consideration of how the standards translate to LMICs settings is required.

Impact

There have been a wide range of impacts resulting from the programme; examples will be discussed here. Undertaking the GEoS in CB1 was considered an extended

role of nursing practice. Now embedded in practice the GEoS has improved access to swallowing assessments as per patient need, providing greater coverage of care and 24-hour access. It has improved the quality of patient care, through immediate management options and patients being given food and drink that they are able to manage. This has involved working in collaboration with the hospitals' dietetic and catering departments to provide modified diets and fluids daily, as part of routine care. In CB1, the GEoS has improved equity, as all hospitals were able to provide swallowing assessments not just to stroke patients, but across different disciplines, and in hospitals without specialist staff in post.

The animations in CB3 were been rolled out at the three IMPROVISE sites, and after completion of the study across three of the IMPROVISATION sites, also to a number of non-stroke-specific wards, and at other hospitals beyond those included in the programme (including: Excel Care Guwahati; Base Hospital Guwahati; Swasti Hospital Rangia; Makunda Christian Hospital; Assam Medical College Dibrugarh; RMRC- IMCR, Dibrugarh; TIMES Hospital, Tezpur; Tezpur Medical College, Tezpur). In a 12-month period, there were > 3000 downloads of the animations, improving access to and the coverage of information provided to stroke patients/carers at the study sites and at other hospitals beyond those included in the programme, reducing the current differences in access to, and availability of, stroke care information due to not being able to afford health care or living a distance away from specialist healthcare facilities.

Following completion of the programme, we have worked in collaboration with the Ministries of Health in Punjab, Kerala, and Assam, delivering three training and dissemination events with over 1000 attendees. In addition, the three CBs within IMPROVISE have been adopted by the NABH providers and form part of national standards for all Stroke Units in India. The NABH has explicitly stated that to gain accreditation, each Stroke Unit must provide education and training on, and demonstrate the implementation of, the three IMPROVISE CBs. They are thus a compulsory component of the national Stroke Unit accreditation process. CMC has become the first stroke first centre in India to be awarded Advanced Stroke Centre status.

Research recommendations

Findings have led to the following recommendations. Further research is required to:

- Conduct a RCT to evaluate the effectiveness and cost-effectiveness of evidence-based CBs (swallowing and hydration, neurological deterioration and post-discharge care) in other LMIC settings.
- Assess the impact of evidence-based CBs (swallowing and hydration, neurological deterioration and post-discharge care) following inclusion in the NABH Stroke Unit accreditation requirements.
- Gain an understanding of post-discharge care provision and the needs of stroke survivors and their carers to inform the development of low-cost rehabilitation services to reduce the burden of care in hospital and community settings and on individuals.
- Develop an Indian-Stroke Competence Framework to inform workforce development and to help ensure that healthcare professionals across the workforce have the right knowledge and skills to deliver specialist stroke care in a range of healthcare settings.
- Explore the variation in the proportions of male/female stroke patients being admitted to hospital and other potential barriers to accessing stroke care.
- Explore the NIHR standards for community engagement and involvement, exploring the barriers and facilitators for how the standards translate to LMICs settings.

Conclusions

Our study provides evidence that recruitment, retention, implementation of the study protocol and evidence-based, context-specific interventions to improve the basic elements of stroke delivery were feasible and could be sustained as an acceptable model of care. Implementation strategies including a co-designed approach, comprehensive training and support, and clinical champions all contributed to enhanced practice and new ways of working.

While improvements were made in acute stroke care, there were gaps in the provision of post-discharge stroke care, which was mainly hospital-based. Patients and carers faced many challenges in accessing post-discharge care, particularly in rural settings. In preparation for discharge, task-shifting among HCPs compensated for a lack of specialists, but limitations were identified in staff education and training.

Our study directly addressed the needs and priorities of healthcare professionals, stroke patients and their carers. PPIE is an essential component of for global health research and PPIE activities should be developed that reflect the local context and account for and adapt to differences both nationally and regionally.

The results of our study will inform larger multi-centre studies, which will provide an evidence base for stroke

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nursing in India. The impact of our research demonstrates that engaging with key stakeholders and policy-makers can result in evidence being translated into practice across healthcare systems.

Additional information

CRediT contribution statement

Stephanie Jones (https://orcid.org/0000-0001-9149-8606): Formal analysis (lead); Project administration (lead); Validation (lead); Visualisation (equal); Writing – original draft (lead); Writing – reviewing and editing (lead).

Elizabeth Lightbody (https://orcid.org/0000-0001-5016-3471): Conceptualisation (lead); Data curation (lead); Funding acquisition (lead); Methodology (lead); Project administration (equal); Supervision (lead); Writing – reviewing and editing (equal).

Elizabeth Boaden (https://orcid.org/0000-0002-4647-6392): Conceptualisation (equal); Data curation (lead); Funding acquisition (equal); Methodology (equal); Project administration (equal); Supervision (equal); Writing – reviewing and editing (equal).

Dominique Cadilhac (https://orcid.org/0000-0001-8162-682X): Conceptualisation (equal); Funding acquisition (equal); Methodology (equal); Supervision (equal); Writing – reviewing and editing (equal).

Andrew Clegg (https://orcid.org/0000-0001-8938-7819): Conceptualisation (equal); Funding acquisition (equal); Methodology (equal); Supervision (equal); Writing – reviewing and editing (equal).

Mark Gabbay (https://orcid.org/0000-0002-0126-8485): Conceptualisation (equal); Funding acquisition (equal); Methodology (equal); Supervision (equal); Writing – reviewing and editing (equal).

Rachel Georgiou (https://orcid.org/0000-0002-0920-0602): Conceptualisation (supporting); Data curation (supporting); Funding acquisition (equal); Methodology (equal); Project administration (equal); Writing – reviewing and editing (equal).

Josephine Gibson (https://orcid.org/0000-0002-3051-1237): Conceptualisation (equal); Funding acquisition (equal); Methodology (equal); Supervision (equal); Writing – reviewing and editing (equal).

Maree Hackett (https://orcid.org/0000-0003-1211-9087): Conceptualisation (equal); Funding acquisition (equal); Methodology (equal); Supervision (equal); Writing – reviewing and editing (equal).

Ranjit Injety (https://orcid.org/0000-0003-1403-8336): Conceptualisation (supporting); Data curation (supporting); Funding acquisition (equal); Methodology (equal); Project administration (equal); Writing – reviewing and editing (equal).

Yogeshwar Kalkonde (https://orcid.org/0000-0003-3543-3618): Conceptualisation (equal); Funding acquisition (equal); Methodology (equal); Writing – reviewing and editing (equal).

Richard Lindley (https://orcid.org/0000-0002-0104-5679): Conceptualisation (equal); Funding acquisition (equal); Methodology (equal); Writing – reviewing and editing (equal).

Pallab Maulik (https://orcid.org/0000-0001-6835-6175): Conceptualisation (equal); Funding acquisition (equal); Methodology (equal); Writing – reviewing and editing (equal).

Sandy Middleton (https://orcid.org/0000-0002-7201-4394): Conceptualisation (equal); Funding acquisition (equal); Methodology (equal); Writing – reviewing and editing (equal).

Jeyaraj Pandian (https://orcid.org/0000-0003-0028-1968): Conceptualisation (lead); Data curation (lead); Funding acquisition (lead); Methodology (lead); Project administration (equal); Supervision (lead); Writing – reviewing and editing (equal).

Gordon Prescott (https://orcid.org/0000-0002-9156-2361): Conceptualisation (equal); Funding acquisition (equal); Methodology (equal); Writing – reviewing and editing (equal).

Kathryn Radford (https://orcid.org/0000-0001-6246-3180): Conceptualisation (equal); Funding acquisition (equal); Methodology (equal); Writing – reviewing and editing (equal).

Caroline Sanders (https://orcid.org/0000-0002-0539-928X): Conceptualisation (equal); Funding acquisition (equal); Methodology (equal); Writing – reviewing and editing (equal).

Padma Srivastava (https://orcid.org/0000-0001-7615-9411): Conceptualisation (lead); Data curation (lead); Funding acquisition (lead); Methodology (lead); Project administration (equal); Supervision (lead); Writing – reviewing and editing (equal).

Anil Sharma (https://orcid.org/0000-0001-4769-3361): Conceptualisation (equal); Funding acquisition (equal); Methodology (equal); Writing – reviewing and editing (equal).

Christopher Sutton (https://orcid.org/0000-0002-6406-1318): Conceptualisation (equal); Funding acquisition (equal);

Methodology (equal); Writing – reviewing and editing (equal).

PN Sylaja (https://orcid.org/0000-0003-4896-8275): Conceptualisation (lead); Data curation (lead); Funding acquisition (lead); Methodology (lead); Project administration (equal); Supervision (lead); Writing – reviewing and editing (equal).

Marion Walker (https://orcid.org/0000-0002-3634-591X): Conceptualisation (equal); Funding acquisition (equal); Methodology (equal); Writing – reviewing and editing (equal).

Caroline Watkins (https://orcid.org/0000-0002-9403-3772): Conceptualisation (lead); Data curation (lead); Funding acquisition (lead); Methodology (lead); Project administration (equal); Supervision (lead); Writing – reviewing and editing (equal).

Doris Schroeder (https://orcid.org/0000-0002-3633-2758): Conceptualisation (equal); Funding acquisition (equal); Methodology (equal); Writing – reviewing and editing (equal).

ODA statement

At the time of the study, our primary beneficiaries of the research in were defined as an LMIC country according to the DAC list. We worked with colleagues within India who were key contributors and leaders in the field of stroke and who held strategic positions in guiding policies within health care and research. We were mindful that the work that we were undertaking needed to guide practice. We developed interventions that will enable the maximum amount of benefit to the most amount of people. We also selected interventions that were appropriate for a low-resource environment. This is in keeping with the principles of ODA.

Data-sharing statement

All relevant data are provided in the synopsis. Requests for additional data should be submitted to the corresponding author.

Ethics statement

Ethics approval (REF: 2020-9715) was granted by the Health Ministry's Screening Committee (HMSC), India (10 December 2018) and each hospital's ethics committee. The study conforms to ethical standards of the ICMR guidelines. In the UK, ethical approval was granted by the Science, Technology, Engineering and Medicine Ethics Committee, University of Central Lancashire (STEM 939). Ethical approval was granted for both written and/or verbal consent, which was obtained from all participants prior to any interviews.

Information governance statement

The University of Central Lancashire is committed to handling all personal information in line with the UK Data Protection Act (2018) and the General Data Protection Regulation (EU GDPR) 2016/679. Under the Data Protection legislation, the University of Central Lancashire is the Data Controller, and you can find out more about how we handle personal data, including how to exercise your individual rights and the contact details for our Data Protection Officer here: www.uclan.ac.uk/legal/data-protection.

Disclosure of interests

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Copyright and credit statement

Department of Health and Social Care disclaimer

Publications

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About this synopsis

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List of supplementary materials

Report Supplementary Material 1
Overview of care bundle content

Report Supplementary Material 2
Global evaluation of swallowing (GEoS)

Report Supplementary Material 3
Links to animations

Supplementary material can be found on the NIHR Journals Library report page (https://doi.org/10.3310/TTDD0404).

Supplementary material has been provided by the authors to support the report and any files provided at submission will have been seen by peer reviewers, but not extensively reviewed. Any supplementary material provided at a later stage in the process may not have been peer reviewed.

The supplementary materials (which include but are not limited to related publications, patient information leaflets and questionnaires) are provided to support and contextualise the publication. Every effort has been made to obtain the necessary permissions for reproduction, to credit original sources appropriately, and to respect copyright requirements. However, despite our diligence, we acknowledge the possibility of unintentional omissions or errors and we welcome notifications of any concerns regarding copyright or permissions.

List of abbreviations

AIIMS	All India Institute of Medical Sciences
BI	Barthel Index
CB	care bundle
CMC	Christian Medical College
CRF	case report form
END	early neurological deterioration
FACTS	fundamentals of acute care and treatment after stroke
FERCI	Forum for Ethics Research Committees in India
GCP	good clinical practice
GEOS	Global Evaluation of Swallowing
HIC	high-income country
HMSC	Health Ministry Screening Committee
ICMR	Indian Council of Medical Research
IIT	Indian Institute of Technology
IMPROVIS-ATION	IMPROVIng Stroke care in India – Advancing The INSTRuCT Operations and Network
IMPROVISE	IMPROVIng StrokE care in India
INSTRUCT	Indian Stroke Clinical Trial Network
IQR	interquartile range
LMICs	low- to middle-income countries
MDT	multidisciplinary team
MOCA	Montreal Cognitive Assessment
MRS	modified Rankin Scale
NABH	National Accreditation Board for Hospitals and Healthcare Providers
NIHSS	National Institute Health Stroke Scale
OT	occupational therapist
PICH	primary intracerebral cerebral haemorrhage
POC	point of care
PPIE	patient and public involvement and engagement
PT	physiotherapist
QASC	Quality in Acute Stroke Care
RA	research assistant
SCTIMST	Sree Chitra Tirunal Institute of Medical Sciences
SLTS	speech and language therapists
SNOBSS	Standardised Nursing Observations Schedule for Stroke
SSS	Scandanavian Stroke Scale
STARS	stroke training and awareness resources
SW	social worker
WP	work package

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