REF2021

Institution: The University of Manchester

Unit of Assessment: 4 (Psychology, Psychiatry and Neuroscience)

Title of case study: Transforming long-term support for stroke survivors - developing and implementing clinical tools that informed national policy and improved regional and national service provision

Period when the underpinning research was undertaken: January 2004 - December 2017

Details of staff conducting the underpinning research from the submitting unit:

Name:	Roles e.g. job title:	Periods employed by submitting HEI:
Audrey Bowen	Professor of Neuropsychological Rehabilitation Reader Senior Lecturer	2016 - present 2015 - 2016 2004 - 2015
Emma Patchwood (nee Patchick)	Research Fellow Research Associate Sabbatical and PhD Trial Manager Research Assistant	2019 - present 2015 - 2019 2010 - 2015 2008 - 2010 2005 - 2008
Andy Vail	Professor of Clinical Biostatistics Reader Senior Lecturer Lecturer	2015 - present 2012 - 2015 2005 - 2012 2000 - 2005
Anne Hesketh	Senior Clinical Lecturer	2001 - 2019
Ruth Boaden	Emerita Professor Professor of Service Operations Management	2020 - present 2004 - 2020
Pippa Tyrrell, MBE	Emerita Professor Chair in Stroke Medicine Senior Lecturer	2017 - present 2012 - 2017 2002 - 2012

Period when the claimed impact occurred: August 2013 - December 2020

Is this case study continued from a case study submitted in 2014? N

1. Summary of the impact

Stroke survivors feel abandoned and uncertain after in-patient discharge. National policy requires six month and annual reviews of survivors' needs but lacked guidance on which tools to use to: 1. review all survivors and 2. support those with specific impairments (communication/cognition). Working with survivors, University of Manchester (UoM) researchers developed, disseminated and evaluated: review and action-planning toolkits (GM-SAT/GM-SAT2) and specific outcome measures (COAST/PRECiS). GM-SAT/GM-SAT2 was recommended in national policy (e.g. NICE, NHS England) and used in >20,000 patients, doubling the reviews previously conducted. Impact included alerting GPs on risk of another stroke (e.g. 11,465 with atrial fibrillation) and improving quality of life. Worldwide, 600 clinicians/educators registered as licensees of COAST/PRECiS, enabling 'person-centred care' for the most vulnerable survivors with stroke-related communication/cognitive impairments.

2. Underpinning research

Fortunately, many of the 100,000 people who have a stroke in the UK each year survive and live long lives, often supported by informal caregivers. To ensure high quality life after stroke, and reduce the risk of a subsequent stroke, healthcare providers must: review all

survivors' and caregivers' needs (physical, psychological and social) at six months and annually thereafter, implement action plans, and monitor specific outcomes for vulnerable subgroups with cognitive and communication difficulties.

Nationally, clinicians' compliance with mandated six month reviews was poor, most likely due to a lack of appropriate clinical tools. Existing approaches tended to be clinicians' assessments of symptom severity/frequency which don't always reflect impact of disability and survivors' needs. UoM research aimed to equip service providers with toolkits (to review patient needs and measure outcomes) that were psychometrically robust yet feasible for use in everyday practice, and acceptable to survivors and caregivers. The team ensured service users' priorities were central to care processes to maximise impact, increasing the likelihood of uptake of the clinical tools and adherence to policy.

Through interdisciplinary, mixed methods research, with strong involvement from stakeholders including survivors and clinicians, the team led on the co-development of tools and approaches that elicited individuals' priorities, identified needs, and evaluated outcomes. These tools contrasted with existing clinicians' assessments. The key steps were:

GM-SAT2: Together, the team and stakeholders developed and evaluated a multi-component toolkit for supporting post-stroke reviews (GM-SAT, GM-SAT2) covering common, long-term needs across health, social and emotional care domains, regardless of whether the individual lives in their own home or a care home.

Tyrrell and Boaden selected the components of the original toolkit - the Greater Manchester Stroke Assessment Tool (GM-SAT) - through consultation with patients, carers and professionals, and published literature. GM-SAT was feasibility tested in an observational and questionnaire study of 137 community-dwelling survivors who participated in a review by trained voluntary sector staff across ten community services in England [1]. The study found that the original GM-SAT was feasible for staff to deliver and acceptable to survivors and caregivers. It identified the types and frequency of unmet needs and that 50% of needs could be met through information-giving rather than requiring referral on.

The toolkit, implemented into routine practice nationwide, was subsequently modified by Bowen and Patchwood through informal feedback and expert consensus meetings, and its reach extended to marginalised care home residents. It was tested across 51 care homes in a mixed methods observational study and via qualitative interviews [2]. It proved to be a useful, comprehensive tool that identified important needs, although assessors required clearer guidance on how to use it and suggested further modifications to the toolkit. These ideas were incorporated into the current version (GM-SAT2) which was disseminated nationwide.

COAST, Carer COAST, PRECiS: Bowen, Patchwood, Hesketh, Tyrrell, Vail and service users co-developed and evaluated novel outcome measures for supporting people with post-stroke communication or cognitive difficulties through literature appraisal, stakeholder involvement to generate content, rigorous psychometric testing and qualitative interviewing:

- Communication Outcomes after Stroke (COAST) measures self-rated communication difficulties and their impact. The COAST was interviewer-administered in community settings with 102 stroke survivors twice in two-weeks to explore acceptability, feasibility of delivery, and psychometric qualities [3]. The companion Carer COAST was validated with 58 informal caregivers (e.g. partners) [4].

- Patient Reported Evaluation of Cognitive State (PRECiS) measures the impact of self-rated cognitive difficulties. PRECiS was interview-administered in community settings to 164 stroke survivors, with 66 participants re-visited to explore test-retest reliability [5].

These studies showed that the COAST, Carer COAST and PRECiS were psychometrically sound, feasible to deliver and acceptable to stroke survivors and informal caregivers [3-5]. They have been made freely available on licence to clinicians and clinical educators locally, nationally and internationally, and to stroke rehabilitation researchers.

3. References to the research

1. Rothwell K, **Boaden R**, Bamford D, **Tyrrell P**. Feasibility of assessing the needs of stroke patients after six months using the GM-SAT tool. Clinical Rehabilitation 2012; 27:3.   http://dx.doi.org/10.1177/0269215512457403

2. **Patchwood E**, Woodward-Nutt K, Rothwell K, Perry C, **Tyrrell P**, **Bowen A**. Six month reviews for stroke survivor care home residents: the value, acceptability and feasibility of a modified review toolkit (the Greater Manchester Stroke Assessment Tool; GM-SAT2). Clinical Rehabilitation 2020 May;34(5):677-687. http://dx.doi.org/10.1177/0269215520912515

3. Long AF, **Hesketh A**, Paszek G, Booth M, **Bowen A**, on behalf of ACT NoW. Development of a reliable, self-report outcome measure for pragmatic trials of communication therapy following stroke: the Communication Outcome After Stroke (COAST) scale. Clinical Rehabilitation 2008; 22 (12): 1083-1094. http://dx.doi.org/10.1177/0269215508090091

4. Long AF, **Hesketh A**, **Bowen A**, on behalf of ACT NoW study. Communication outcome after stroke: a new measure of the carer's perspective. Clinical Rehabilitation 2009; 23, 846-856. doi: http://dx.doi.org/10.1177/0269215509336055

5. **Patchick E**, **Vail A**, Wood A, **Bowen A**. PRECiS (Patient Reported Evaluation of Cognitive State): Psychometric evaluation of a new patient reported outcome measure of the impact of stroke. Clinical Rehabilitation 2016; 30 (12), 1229-1241. http://dx.doi.org/10.1177/0269215515624480

Research funding

- **COAST** - Bowen A (PI), Tyrrell P, Vail A, et al. The ACT NoW study: Assessing Communication Therapy in the North West, NIHR HTA, GBP1,400,000, 2004 - 2010.

- **PRECiS** - Patchwood E (PI), Vail A, Bowen A. Developing a comprehensive, patient-centred outcome measure to evaluate the effectiveness of cognitive rehabilitation after stroke. Stroke Association, GBP105,000, 2011 - 2015.

- **GM-SAT2** - Boaden R (PI), Bowen A, et al. NIHR Collaboration for Leadership in Applied Health Research & Care Greater Manchester infrastructure, matched and extension funding GBP21,750,000, 2014 - 2019.

- **GM-SAT** – Sibbald B (PI), Boaden R, Tyrrell P et al. NIHR Collaboration for Leadership in Applied Health Research & Care Greater Manchester infrastructure and matched funding GBP20,000,000, 2008 - 2014.

4. Details of the impact

Context

Stroke is a life-changing event affecting approximately 100,000 individuals in the UK every year, many of whom experience long-term disability and feel "abandoned" after discharge from hospital. Despite national policy to provide six month reviews of *all* stroke survivors' needs, the Sentinel Stroke National Audit Programme (SSNAP) national audit of stroke care provision repeatedly found that very few survivors received a review. Similarly, a high priority for service users was improved care and outcomes for vulnerable people with specific post-stroke psychological (e.g. cognitive) and communication (e.g. aphasia) difficulties. The team used research to: produce tools to improve care, influence national policy and guidance, increase the number of reviews conducted nationally and regionally, and improve outcomes regionally, nationally and internationally.

(i) Pathways to impact - GM-SAT2

The team raised awareness of the original GM-SAT and expanded GM-SAT2 toolkits for conducting mandated six month reviews of needs, presenting at key national conferences such as the annual UK Stroke Forum attended by approximately 1,400 professionals, making the toolkit freely available for download from the team's website and publishing in a

leading multidisciplinary journal accessible to service providers. This exposure generated significant interest evidenced by promotion of the toolkit by influential bodies (e.g. NHS England, British Association of Stroke Physicians) and policy-makers (e.g. NICE, Intercollegiate Stroke Working Party) to service providers including the national organisation representing stroke survivors (Stroke Association). Regionally across Greater Manchester the team worked closely with the Stroke Operational Delivery Network (GM-SODN), supporting them in their roll-out and auditing of use of GM-SAT2 as part of their service improvement plan. The research team collaborated in training over 250 service providers in the use of the GM-SAT2.

Reach and significance of the impact - GM-SAT and GM-SAT2 directly influenced:

National policy and guidance for Patient-Centred Care after stroke including:

- British Association of Stroke Physicians' (BASP) six-month review policy [A].
- NICE Stroke in Adults, Quality Standards 2, QS7, priorities for quality improvements [B].
- The NHS England CQUIN, Commissioning for Quality & Innovation framework supports improvements in the quality of NHS services and patterns of care [C].

National implementation into clinical practice – GM-SAT2 is now commissioned for six month reviews by Stroke Association staff in 42 services across England, Wales and Northern Ireland. More than 20,000 stroke survivors have had a GM-SAT review and annual review performance has almost doubled since 2013 [D].

In 2019 Stroke Association said the tool is: "*helping our staff to work with the person to identify any unmet needs… and to put in place any support they need to continue to rebuild their lives after stroke*" [D].

Transforming care in Greater Manchester – The collaborative development of the GM-SAT2 resulted in exceptional uptake in Greater Manchester where it was implemented routinely across all 12 clinical commissioning groups. Annual review performance increased 2.5 fold regionally since 2013 to around 1200 per annum.

In 2019 the Greater Manchester Stroke Operational Delivery Network said: *"The exclusive use of GM-SAT by all providers of 6 month reviews in the region's stroke pathway has enabled… service evaluation to better identify and understand patterns of unmet needs of patients in the longer term. These data will inform improvements to the provision and commissioning of life after stroke support for all our residents*" [E].

Improving service provider competence – Clinicians value the use of the GM-SAT2: *"You are better at doing your job, you are more effective….and you can help people to recover more, that's what we're here for, isn't it."* Quote from an NHS Assistant Practitioner [F].

Improving patient outcomes - For 23,000 stroke survivors who received a review by Stroke Association using the GM-SAT/GM-SAT2, 150,000 unmet needs were identified and reported to GPs to: reduce recurrence of stroke (e.g. 11,000 people with atrial fibrillation) and improve independence (mobility needs 7,000) and quality of life (fatigue 12,000*)* [D].

(ii) Pathways to impact - COAST, Carer-COAST and PRECiS

The team raised awareness of these person-centred outcome measures for people with specific psychological and communication difficulties, presenting at leading national conferences, publishing in accessible journals and making them free to download through the UoM's Intellectual Property team via the former *Click2Go* platform (now *Innovation Factory*). This exposure led to collaborations for translations into several languages and generated significant interest e.g. 600 licenses awarded to clinicians/clinical educators worldwide.

Reach and Significance of the impact - COAST, Carer-COAST and PRECiS

Half the 600 registered licensees were from outside the UK. Respondents to a request for feedback reported the measures were instrumental in improving care and recovery:

Improving clinical care and communication with patients

"… invaluable... the COAST is accessible, enabling stroke survivors to respond, even if they have difficulty speaking. … allows patients and their families to let us know how the stroke is affecting their communication and quality of life in daily, real life situations. As such the COAST is an improvement upon … existing assessment tools…. It allows the voices and the needs of stroke survivors to be better heard." Professor of Speech and Language Pathology, Canada [G].

"… impact of… COAST is increased understanding of the effect of the communication difficulties on the individual's life. It can… help with identifying functional goals for therapy. With the carer COAST …it has helped … them to open up… This has then led to helping them access support." Speech and Language Therapist, UK [G].

Evaluating interventions from a person-centred perspective

"*I really enjoy using the COAST to gauge my patients' perceptions of improvement. I also like to use it as tangible evidence that they are improving. A lot of times my patients don't feel like they've improved and then after they retake the COAST they report that they do feel they have."* Speech and Language Therapist, Bermuda [G].

Improving patient recovery

Importantly the team solicited feedback on impact directly from a stroke survivor *"Using these tools on the journey of recovery from stroke validated my individual perspective on the difficulties I was still facing. It engaged me to continue working as much as possible to recover and find ways around those difficulties."* Stroke Survivor [H].

"We have been able to demonstrate a clinically and statistically significant reduction in PRECiS scores over the period of our 10 week program." Senior Lecturer Occupational Therapy, Australia [G].

5. Sources to corroborate the impact

A. British Association of Stroke Physicians policy 2015. BASP recommendation for providing 6 month review signposts to the GM-SAT.

B. National Institute of Clinical Excellence (NICE). Stroke in Adults. Quality Standards 2, QS7. Updated April 2016, recommends GM-SAT.

C. The NHS England CQUIN 2019 NHS England Stroke plan and CQUIN, giving practical guidance on tools to support a review process - GM-SAT is the first tool recommended.

D. Letter and data extraction from Director of Stroke Support, Stroke Association from 2020, noting how the GM-SAT has changed service delivery (e.g. over 20,000 reviews conducted) and improved patient care (e.g. over 150,000 unmet needs identified).

E. Letter from Manager of NHS Greater Manchester Stroke Operational Delivery Network (GM-SODN) from 2020, on how collaborative development of GM-SAT supported its uptake and the improvements in stroke care that GM-SAT has facilitated across the region.

F. Quote from NHS Assistant Practitioner that GM-SAT2 enables her to do her job more effectively, spoken at 3.45 minutes into this 4 minute video from December 2018 https://www.arc-gm.nihr.ac.uk/projects/gm-sat-2.

G. Quotes* from Click2Go licensee respondents [*edited for brevity], from November 2019 to November 2020, on use of PRECiS and COAST noting impact on improving clinical care and evaluating interventions.

H. Quote from Stroke Survivor, from August 2020, noting the importance of using patient-centred measures to support engagement and recovery post-stroke.