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## EBN Opinion Piece

### **Title: Co-creation and co-production in health service delivery: what is it and what impact can it have?**

This May marked Action on Stroke month and in recognition of this, EBN hosted a special week of blogs written by stroke survivors, practitioners and stroke researchers and a twitter chat focussing on priorities in the management of acute and long-term stroke. The blogs can be found online (<https://blogs.bmj.com/ebn/>) as well as a blog summary of the twitter chat (<https://blogs.bmj.com/ebn/2019/05/17/summary-of-twitter-chat-action-on-stroke-month-priorities-in-the-management-of-and-research-on-stroke/>). One of the discussion threads that emerged during the twitter chat focussed specifically on approaches to co-creation and co-production in the development and delivery of person-centred stroke services (Figure 1). One of the contributor's was Daniel Wolstenholme (@wolstenholme\_d) who shared his experiences. In this edition of the EBN Opinion, we follow up on this particular thread with Daniel to find out more about the type of co-production work he has been involved in leading.

### **Background**

The first major publication on co-creation was by Greenhalgh, who explored achieving research impact through co-creation.<sup>1</sup> Greenhalgh positioned co-creation as a form of collaborative knowledge generation between academics and other stakeholders. This is to say that academics should be answering the questions that the stakeholders (service providers and those in receipt of services) want answering, and working with those stakeholders to answer those questions.

In the academic literature this process is called 'knowledge mobilisation' and has largely focussed on getting evidence into practice; that evidence has tended to be in the form of research outputs. For a useful summary of the state of the art of Knowledge Mobilisation (also referred to as Implementation Science) I would wholeheartedly commend Per Nilsen's paper.<sup>2</sup>

The description of knowledge that is generated by academics and then 'used' by stakeholders is 'Mode 1 Knowledge Mobilisation'.<sup>3</sup> A more nuanced and sensitive approach to this process is described as 'Mode 2 Knowledge Mobilisation'.<sup>3</sup> 'Mode 2' recognises different forms of knowledge; practical knowledge, tacit knowledge, procedural knowledge, local knowledge, and recognises that this knowledge has to be generated within and be sensitive the context of its use.<sup>3</sup> In its bluntest form this means that there is no use for a guideline that recommends that everyone should have a CT scan, if there isn't a CT scanner for 20 miles.<sup>4</sup>

This process of 'doing' 'Mode 2 Knowledge Mobilisation' has been described as co-creation or co-production. Co-production is a frequently used term, which is used somewhat uncritically but in its best form speaks to a genuine and meaningful engagement between the key stakeholders to generate new knowledge that is sensitive to context<sup>5</sup> and thus, is more likely to be implemented. The 'co' prefix is important as that is where the moral and pragmatic arguments to involve people is driven from. Morally, people whose lives are affected by a change have a right to be involved and pragmatically, by involving those people you will get a better outcome.<sup>6</sup>

This brings us to the EBN Twitter Chat where the focus was around stroke and service provision. We discussed two projects we had been involved whose aim was to support co-production or co-creation.

**EBN** **EBNursingBMJ** @EBNursingBMJ · 15 May

Onto our next question: Q3. How can we involve stroke survivors and their families in a more collaborative way? #ebnjc #actionstroke

**Evidence-Based Nursing #ebnjc**

Encouraging best practice in nursing

**Question 3**  
**How can we involve stroke survivors and their families in a more collaborative way?**



Join our online communities:  
[@EBNursingBMJ](#)  
[/BMJnursing](#)

1 1 2

**daniel wolstenholme** @wolstenholme\_d

Replying to @EBNursingBMJ

#ebnjc we did this project @Rob\_zone83 clahrc-yh.nihr.ac.uk/our-themes/tra... using creative codesign to meaningfully engage people @Lab4Living

8:51 pm · 15 May 2019 from Sheffield, England · Twitter for iPhone

Replying to @lisakidd22 @EBNursingBMJ and 2 others

A critical mass of expertise in #Sheffield @Lab4Living @CLAHRCYH

9:00 PM · May 15, 2019 from Sheffield, England · Twitter for iPhone

2 Likes

1 1

**daniel wolstenholme** @wolstenholme\_d · May 15

Replying to @wolstenholme\_d @lisakidd22 and 4 others

#ebnjc

1 1

**Lisa Kidd** @lisakidd22 · May 15

Replying to @wolstenholme\_d @EBNursingBMJ and 3 others

Be great to chat to you more about your experiences :-)

1 1

**daniel wolstenholme** @wolstenholme\_d · May 15

Of course, if you check out of webpages you will see a number of examples of our work clahrc-yh.nihr.ac.uk/our-themes/tra... we have worked with the fab @nickayes4 too! So Glasgow is positively local 😊

1 2

**Lisa Kidd** @lisakidd22 · May 15

**daniel wolstenholme** @wolstenholme\_d · May 15

Some great coproduction codesign work coming out of @GSofA @gem\_wheeler would know more!

1 2

**Lisa Kidd** @lisakidd22 · May 15

Brilliant, thanks so much Daniel!

1 1

**Nicola Kayes** @nickayes4 · May 15

Fab to see you connecting into this discussion @wolstenholme\_d love your work! @wolstenholme\_d @JoelLangley\_ @Lab4Living are doing heaps of great work and I love love working with them and our own local peeps @goodhealthdesn

1 3

## Figure 1 Twitter chat

The first project explored the issue of weight gain after stroke in response to recent research which had highlighted that weight-gain was a problem for some people after stroke.<sup>7</sup> The project raised for discussion considered how to improve weight management services for stroke survivors in Sheffield. The aim was to identify interventions, actions or products that could improve current provision of weight management services and support and improve patient experience. The various groups involved were stroke survivors and carers, staff involved in the stroke pathway, and public and third sector service providers. Firstly, we met to discuss current stroke service provision and develop a map of available weight management stroke services. Secondly, co-production took place. Two workshops were used to collaboratively identify areas for development and generate ideas for how changes could be made in service delivery and resource provision to addresses key gaps. During the consultation, people identified several areas for development. Staff and stroke survivors wanted more accessible resources to help stroke survivors access weight management information. They expressed a need for education on diet and weight management. Staff said that training was needed to build their own confidence and skills in addressing weight management. Specific areas for training were nutrition, facilitation of behaviour change, and understanding stroke impact for staff not trained in stroke care. Staff also reported that increased knowledge of current services would help them signpost patients more appropriately and wanted clear ways to refer stroke survivors for services.

In the co-production workshops, ideas for changes in service delivery to address these issues were discussed. This included longer-term services for post-stroke lifestyle. Health trainers, and the voluntary sector support services could be sources of this service provision. More information could be in the form of a 'cook book' containing advice, recipes, and educational material for stroke survivors and their carers. A lifestyle questionnaire, based on Motivational Interviewing principles, might support staff and stroke survivors in identifying goals and facilitating lifestyle changes. Dietetic input for weight-gain on the stroke pathway was also an idea. The full report is available [here](#).<sup>8</sup> Although the impact of the co-production process on the services and strategies identified needs further evaluated, the co-production process was perceived by stakeholders to have been valuable for developing weight management resources because they were involved in the conception and design of the weight management resources. This enabled these to be tailored towards peoples' needs and thus, truly person-centred.

In recognition of the importance of exercise in promoting recovery and rehabilitation from stroke and preventing secondary stroke,<sup>9</sup> the second project was initiated to explore ways to promote exercise in stroke survivors living in Sheffield (UK) using co-production workshops. Based on the people's experiences of accessing exercise services in Sheffield and using co-production methods, we intended to:

- understand current service delivery around exercise for stroke survivors
- understand perceived myths and enablers/barriers to exercise
- network with various care and industry organisations to understand what types of physical activity are available for people with disability to participate in across Sheffield;
- explore ways in which the services could be improved

The multidisciplinary core team, comprising health professionals and designers, co-facilitated a series of five workshops. This project was part of getting research into practice (GRIP) and funded by the National Institute for Health Research Collaborations for Leadership in Applied Research and Care Yorkshire and Humber (NIHR CLAHRC YH). Throughout the project, 71 people were involved. At least 15 participants were involved in each workshop. The workshops gathered together stroke survivors (all within the past 5 years), health care professionals, exercise prescribers, social services, commissioners, medics and representatives from the voluntary sector. The first three workshops consisted of approaches to understand the participants' experiences, which included creative activities

such as asking participants to create a 'fake news' story about myths they had heard in relation to physical activity after stroke (Figure 2), a specially designed template to help participants think about potential barriers and facilitators to exercise following stroke (Figure 3), and personal biogs about their experiences of stroke, health services and motivations to exercise following stroke (Figure 4).



Figure 2 Using a fake headline to find out about myths around exercise

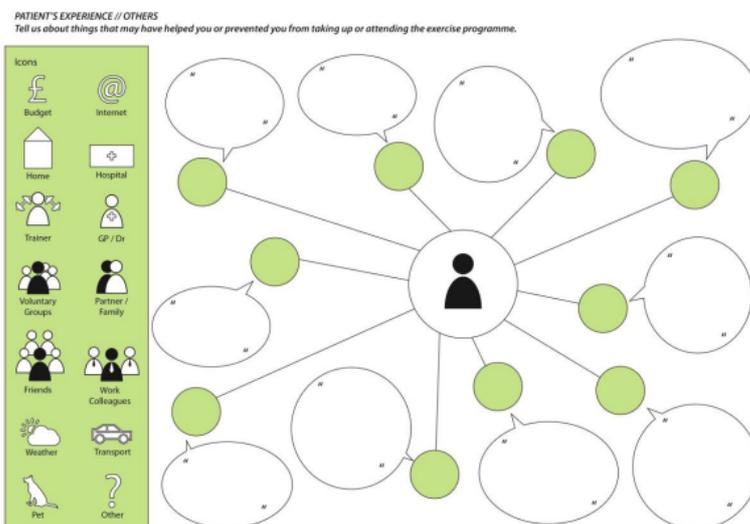


Figure 3 Identifying barriers and enablers to exercising following a stroke

**Who am I?**

I am a... *nurse* | I am from... *White Berrish*

My name is *Jane* | My age is *22*

My living situation is... *Sheffield St. Flatsmate, no responsibilities. Drives.*

Characteristics to describe me are... *Bubbly, fun, kind, compassionate, has a bit of a wild side, happy.*

Things that are important to me are... *Socialising, Rother Valley, water sports, gym.*

Something I enjoy... *Drinking (on night out)* | Something I dislike... *Very early mornings.*

It might surprise you to know that... *Career focused, very committed to learning more & developing in a particular area.*

**About Stroke**

My motivation to exercise is... *SMART goals. Get my team to think of small goals (achieve, achieve, motivation count) & Drive it home (walking around the block or spinning) then home from 10k to 15k to 20k.*

My concerns are... *Not enough time to spend with pts. Limited information & resources. Decline in support. Lead to less rehab & increased demand on social care. Pts less able to be independent.*

My experience of Stroke's services is... *No consultation in the service. Disjointed services.*

The services work well for me when... *Tries to give support & advice as to where to go after leaving hospital. To encourage pts to keep pursuing information & never give up.*

I find the service difficult when... *The lack of official pathways means some get everything & others get nothing.*

Figure 4 a persona created by a mix of staff and stroke survivors

These activities allowed for 'reflections' to be uncovered. Following this, undergraduate design students involved with the project were paired with stroke survivors and healthcare professionals to jointly develop ideas around ways to improve current service provision (Figures 5 and 6).

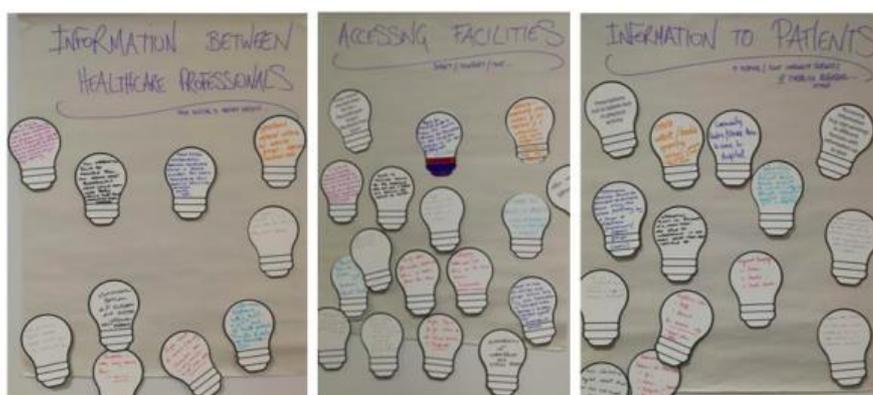


Figure 5 Ideas generated through the co-production workshops



Figure 6 one of the ideas developed by the students and pitched to the participants

Five outputs emerged from the research: a marketing campaign to burst myths and promote physical activity, a video raising awareness of the benefits of promoting exercise, a staff training package about information delivery regarding exercise, a stroke survivor's passport to access relevant and customised information while keeping one's medical record in one place, a buddy box to increase wellbeing among survivors. A full report of how the workshops were undertaken, who was involved and the resources developed is available [here](#).<sup>10</sup>

### To summarise...

The Twitter Chat for Action on Stroke Month highlighted the importance and wealth of knowledge that our Twitter community have around activities which support co-production, co-creation and genuine and meaningful involvement. It is common sense that you should involve people in developing new services, however all too often, as a community, health and social care practitioners and researchers think that it is enough to simply get people together in a room. Over the last ten years of work the NIHR funded CLAHRC (<http://clahrc-yh.nihr.ac.uk/our-themes/translating-knowledge-into-action>), and colleagues at Lab4Living ([www.lab4living.org.uk](http://www.lab4living.org.uk)) have demonstrated that the attention to the conditions for coproduction to happen is as important as getting people together. We argue that by using creative methods and making things tangible it allows people the genuine opportunity to contribute their expertise to a process that delivers person centred services and care.<sup>11,12</sup> The involvement of creative practitioners drawn from design and related disciplines allows this process to deliver the potential that co-creation offers.

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