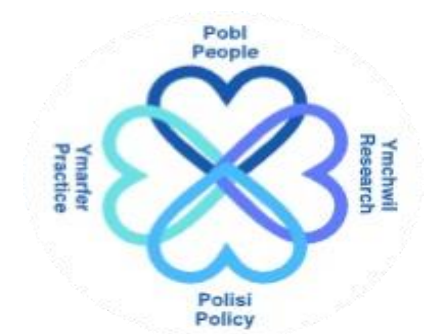
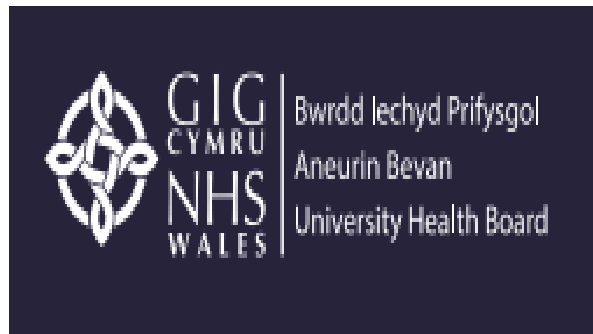


# What matters most in Neurorehabilitation?

Daryl Harris, Linda Tremain, Tarrin Triplett, Nick Andrews

This brief report summarises the use of the Most Significant Change (MSC) approach as part of the evaluation of the ABUHB Neuro-Stute Neurological Conditions Recovery College. This evaluation was undertaken with the support of the Bevan Commission Exemplar Programme and Swansea University's Developing Evidence Enriched Practice (DEEP) Team



The Neuro-Stute is a shared initiative between people living and working with long term neurological conditions. The intended outcome for the 'Stute' is to provide a prudent approach to health and social care built on a sustainable and collaborative contract between service recipients and providers. If you are interested in learning more about the Stute, please contact us using the contact details below.

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We are indebted to the participants in our Story Selection Panel who were:

**Nick Andrews** (Research and Practice Development Officer, Developing Evidence Enriched Practice)

**Jenny Clarke** (Brain Injury Survivor and Chief Executive Officer, Same You Brain Injury Charity)

**Rhiannon Edwards** (Former Neurological Conditions Implementation Group Coordinator)

**Philip George** (Stroke Survivor and former Chair of the Arts Council For Wales)

**Adele Griffiths** (Head of Community Neuro Rehabilitation Service (CNRS), ABUHB)

**Daryl Harris** (Consultant Clinical Psychologist, CNRS, ABUHB)

**Tom Howson** (Innovation Lead for the Bevan Commission)

**Jane Mullins** (Stroke Hub Wales- MRes(stroke) lead, Cardiff Metropolitan University)

**Nicky Needle** (Integrated Service Manager Y-Fenni / Integrated Wellbeing Network Lead, Monmouthshire Social Services)

**Rebecca Pearce** (Chief Executive Officer Headway Cardiff & South-East Wales)

**Tanya Strange** (Head of Nursing for Person Centred Care, ABUHB)

**Linda Tremain** (Specialist Neuro physiotherapist, CNRS, ABUHB)

**Tarrin Triplett** (Assistant Psychologist, CNRS, ABUHB)

**Most Significant Change (MSC)** is an approach to evaluation that was developed in the context of complex and messy public health initiatives, where control is limited and outcomes uncertain.

It starts by gathering stories from the frontline which are focused on capturing *change outcomes* that have resulted from an intervention or programme. In this study seven stories of positive change were collected from a representative sample of participants, peer partners, and professionals contributing to the Neuro-Stroke Recovery College.

The MSC process has 3 stages: (1) Gather stories of change from the frontline; (2) Explore and learn from the stories in story selection panels attended by managers and people who can influence policy and practice development, and (3) Provide feedback on what has been learnt and the implications for policy and practice development.



# Seven significant change stories were discussed by the selection panel

The significant changes highlighted in these stories are summarised in the following pages of this brief report.

## Collaboration is Key



If either side of the partnership wasn't there, the service wouldn't be successful. If you haven't got the National Exercise referral Scheme (NERS) team present, then you aren't getting people into the community, If the health professionals were not there, then the NERS team wouldn't have the confidence or experience to work with these complex individuals. There have been problems along the way, but the team work together to learn from this and improve the service as they go.

## Bouncing from Amber to Red



Recognising when I am at risk of getting fatigued, recognising when I am in amber rather than bouncing between amber and red. This gave me more control over my fatigue so that I can engage in other helpful activities.

## It's a Two-Way Street

Improved confidence in presenting - this was a challenge that I chose to take on and I feel proud of pushing myself out of my comfort zone. It has been an important learning experience and helped me in other aspects of my work.

## Brain Fog Breakfast Club

Learning and building acceptance. I was fighting with the new version of myself to get back to the old version. Now I feel more comfortable and prepared to find peace with "version 2 of Dave"



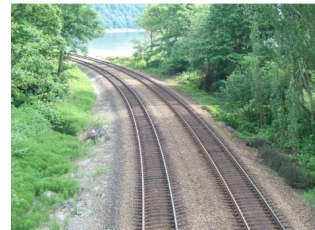
## Act Now

There is considerable demand for psychological support in people recovering from stroke and brain injury. My work within the Recovery College gives me more hope that we will be able to facilitate access to this support in a timely way.



## Stuck on the Tracks

Understanding that this is how Jack's brain now works. It's like he is on a train from A to B and he can't get off.



## Wendy's Lush Story

The most significant change for me was becoming a peer partner with the Recovery College.





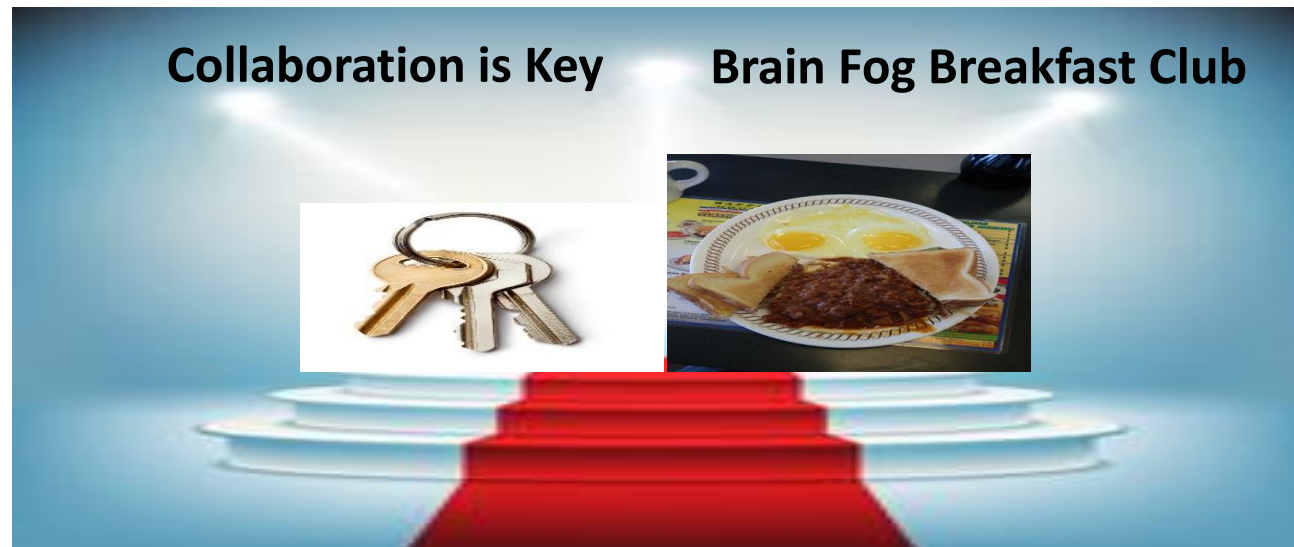
# Selection Panel Discussions

The selection panel spent nearly five hours discussing the seven stories. Each story was highly valued for different and overlapping reasons. In the end the panel chose two stories. The reason for selecting two stories rather than one was because one was told from the perspective of a member of staff and the other from that of a participant and peer partner. However, this categorisation of stories into themes from service recipients and providers was also questioned by the panel who recognised that many of the themes and changes discussed had relevance to everyone involved in the recovery college. This is acknowledged below in a theme labelled 'shared spaced for learning and growing'.

*'Collaboration is Key'* was scored most highly by panel members. The things panellists valued about this story included the importance of "bottom-up" and "suck-it-and-see" service developments that facilitate learning from "small steps" and "growing organically" and in relationship with partners in a shared process of learning. This was contrasted with top-down development of impersonal pathways. The organic nature of this process also recognised the value of integration and interconnectedness in terms of mind, brain, and body; individuals and their families; families and their communities; and service providers and people accessing services.

A very close second was the *'Brain Fog Breakfast Club'*. The things panellists valued about this story included the journey from the implied pain from loss of role and occupational status, to the story-teller re-inventing themselves, rediscovering meaning and purpose in life, and then using their experience of stroke recovery and life skills to make new connections and to help other

people recovering from stroke and brain injury. The panel discussed aspects of the recovery college model that helped in catalysing this re-invention. These included a personal focus on the individual, participants' ability to influence how things are run, and the emphasis on shared experience, acceptance, and moving beyond stroke as the focus of connections to the development of friendships.



The next page presents a summary of the themes arising in the panel meetings. These are divided into three groups of themes. The first group of themes relate to aspects of **service structure** valued by stakeholders. The second group of themes speak to the quality of **relationships** within these structures. The final group of themes refer to the valued **outcomes** (or impacts) of these interactions.

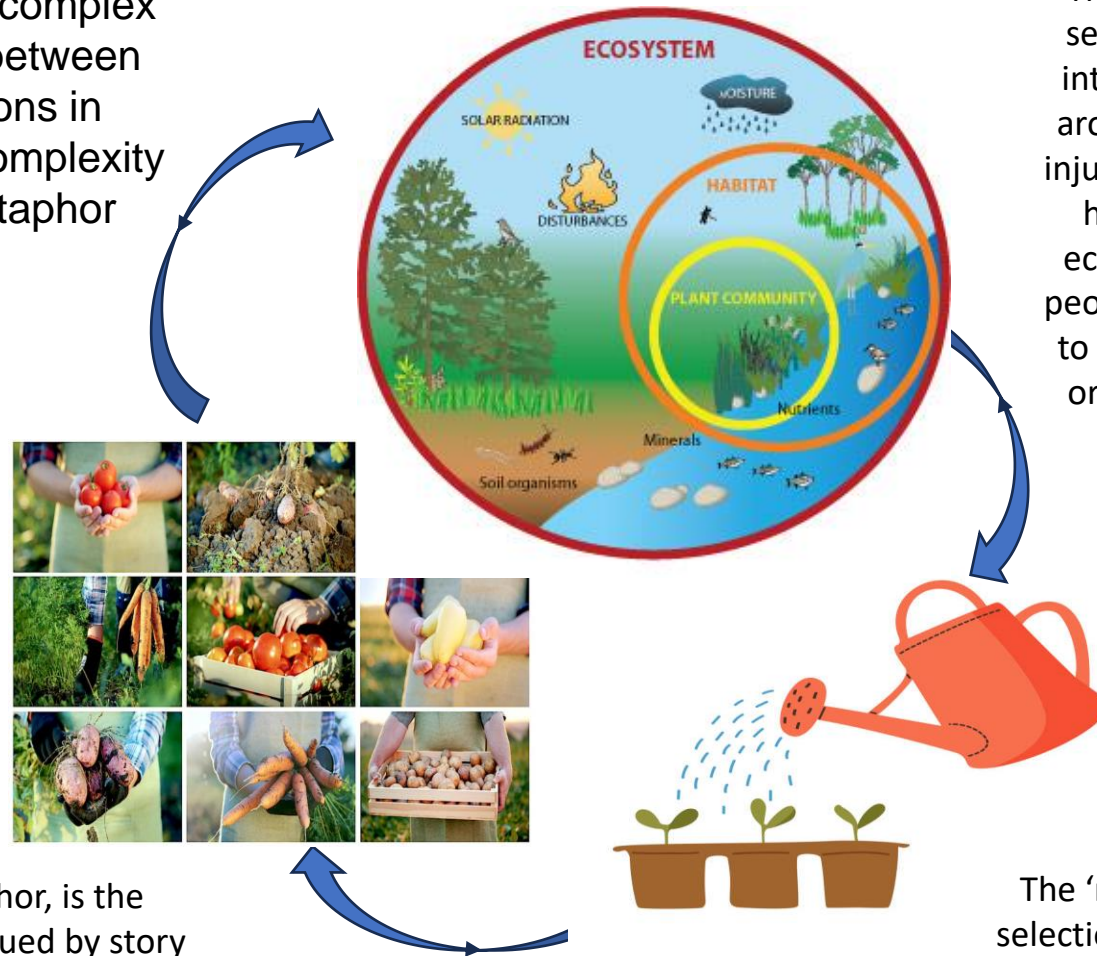
## Themes in the significant change stories valued by selection panel members

### Labels and descriptions of themes seen as important by panel members

<b>Services</b>	<b>Inter-relationships and ripple effects</b>	This theme recognises the interrelated nature of the impact of brain injury, stroke, and personal recovery on family, friends, the communities and communities of practice supporting people.
<b>Services</b>	<b>Integrated care</b>	This theme highlights the importance of integration across services and sectors.
<b>Services</b>	<b>Integrating psychological &amp; physical recovery</b>	This theme highlights the value of integrating psychological and physical health and mental and physical health services.
<b>Services</b>	<b>Flexible &amp; responsive services</b>	This theme recognises the need for practitioners to feel safe and supported to develop services and ways of working that are responsive to what matters to citizens and that can grow organically.
<b>Services</b>	<b>Services embedded in local community</b>	This theme relates to the value of embedding rehabilitation within everyday contexts.
<b>Services</b>	<b>Sustainable focus on community capability</b>	This theme recognises the importance of empowering people to use their experience and capabilities to support other people recovering from stroke and brain injury, and the impact of this on sustainability
<b>Services</b>	<b>Shared spaces for learning and growth</b>	This theme recognises the value of creating safe places for practitioners and people with lived experience to learn with and from each other.
<b>Relationships</b>	<b>Sharing personal experience &amp; expertise</b>	This theme highlights the power of sharing stories of personal experience in making sense of the impacts of brain injury and in creating a sense of hope and being understood.
<b>Relationships</b>	<b>Sharing power and influence</b>	This theme highlights the importance of freeing professionals from unhelpful beliefs about responsibility and agency.
<b>Relationships</b>	<b>Maximising personal autonomy and agency</b>	This theme highlights the importance of flattening power dynamics and maximising opportunities for shared influence and decision making.
<b>Outcomes</b>	<b>Facilitating Acceptance</b>	This theme highlights the value of sharing personal stories in helping people to make sense of their situation and supporting self-acceptance.
<b>Outcomes</b>	<b>Facilitating reinvention – rediscovery of self</b>	This theme highlights the value of facilitating ways for people to reinvent themselves as part of their recovery. Reinvention does not mean letting go of old me but finding ways of bringing old me into the current reality.
<b>Outcomes</b>	<b>Increased sense of connection</b>	This theme describes the importance of connection as an outcome supporting wellbeing, recovery and discovery.
<b>Outcomes</b>	<b>Focus on sense of purpose, meaning, value</b>	This theme describes the importance of (re)discovering a sense of purpose, meaning, and self-worth / pride.

# A metaphor with an ecosystem

An overarching observation was the complex interactions and interdependencies between the themes arising from the discussions in the selection panel meetings. This complexity appears to be well captured by a metaphor with an ecosystem.



## The Harvest

The final aspect of the ecological metaphor, is the harvest. This is the outcomes that were valued by story tellers and the members of the selection panel. This harvest includes the fruits of acceptance, reinvention, connection, purpose, meaning, and value. This harvest both arises from and sustains the ecosystem.

# The Ecosystem

The comments made by panel members about service structures can be seen as reflecting the integrated nature of the ecosystems within and around people recovering from stroke and brain injury. Panel member's comments can be seen as highlighting the need for habitats within this ecosystem that support services, professionals, people participating in services, and communities to be able to work together to grow flexible and organic responses to the challenges and needs arising from brain injury and stroke.

## Nutrients

The 'relational' factors highlighted by the selection panel members can be seen as the nutrients that support growth. These include the nourishing impact of sharing experience, stories, power, and influence.