

Research agenda influenced by patient involvement

Sarah Dean, Senior Lecturer in Health Services Research, explains what the ReTrain study is and how it became a PenCLAHRC project which aims to improve health outcomes for patients and the public through the conduct and translation of patient-focused research.

Patient involvement

Jim is 77 years old and had a stroke nine years ago. He was offered the conventional approach to rehabilitation during the first year after his stroke, which he found valuable. However, he felt that the health service then stopped expecting him to improve. He was given a leaflet about Action for Rehabilitation from Neurological Injury (ARNI) and decided to find out more. As a result, he suggested to members of the Peninsula Stroke Network Public Involvement Group the idea of researching the effectiveness of ARNI. Jacqueline Briggs (the Stroke Network Manager) worked with Jim to develop the idea. She then met with Andy Gibson, PenCLAHRC's Patient and Public Involvement Research Fellow, and they developed Jim's thoughts into an outline research question and submitted it to PenCLAHRC.

It was prioritised and PenCLAHRC is now developing it into the Re-Train research project.

ARNI

ARNI was formed in 2001 by Dr Tom Balchin, who has also survived a stroke. This was as a response to the very real demand throughout the UK from the large number of community-dwelling stroke survivors who do not require full-time care in a dedicated facility yet uniformly stated that they were 'stuck in limbo' after coming home from rehab.

The ReTrain Study

Our initial review of the evidence indicates that there is a paucity of research evaluating the outcomes of such longer term rehabilitation for people who have already been discharged from initial rehabilitation services following their stroke. Our research question is therefore: for people who are one year on from stroke, how does the Action for

Rehabilitation from Neurological Injury (ARNI) training programme compare to a usual care package involving primary care exercise prescription, in terms of better health and quality of life outcomes? We aim to answer this by conducting the ReTrain study, a pilot and multi-centre pragmatic randomised clinical trial of the Action for Rehabilitation from Neurological Injury training programme for survivors one year on from stroke. Jim and members of the Stroke Network Public Involvement Group will continue to be involved in the project.



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Engaging with service users

Martin Jenner, Chairman of Diabetes UK – North Devon Branch, describes his experiences at a workshop organised by Andy Gibson, Research Fellow for Patient and Public Involvement.

This was one of the most practical and enjoyable workshop that I have attended. What was different about it? The difference was rooted in the purpose of PenCLAHRC. Some organisations seek patient involvement to inform and guide the work of others or to provide ideas that others can develop into new, or incorporate into existing, research projects. PenCLAHRC involves patients and carers in the process of developing research questions and working them up into projects.

The starting point in this workshop was similar to that used in others I have attended, namely to work in small groups to identify areas of concern that could lead to research. The materials used were effective in helping those who attended to take a logical approach to refining those ideas and phrasing research questions.

The real difference is in the fact that the opportunity exists for each and every participant to work, with the PenCLAHRC team, questions will be considered on equal terms with those submitted by clinicians and research scientists. The process, through which we were expertly guided, is also available online through the PenCLAHRC website (<http://question.penclahrc.com/>).

Whilst other events have been informative and enjoyable, I came away with a real feeling that for the first time my ideas (some of which had been aired in other forums) had a chance of moving forward, with my involvement, into real research.



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Derriford exemplar site for VTE!

In late December 2009 Derriford Hospital, Plymouth became an Exemplar Centre for Venous Thromboembolism (VTE) Prevention. Derriford was inspected by the Department for Health team when they attended Derriford's VTE awareness day. VTE is thought to account for as many as 25,000 preventable deaths annually in hospitals in England. PenCLAHRC is working on behalf of NHS Southwest to research and evaluate the implementation of preventative screening and treatments.



PenCLAHRC Staff Interview

Name: Tracey Jones-Hughes

Job Title: Project Facilitator

Describe your role within PenCLAHRC:

I coordinate activities within projects and encourage progress by any means possible!

Who would you most like to have dinner with (past or present)?

The people I had every intention of staying in touch with, but haven't spoken to for years.

What is your greatest extravagance?

GHD hair straighteners (hard to believe I know!)

What is your most precious possession?

If a person can be a possession then I would say my children. After that, I guess it would be my old BMW convertible, which my husband has convinced me is a classic.

What do you value most in a friend?

Honesty, combined with a dry sense of humour.

If you had a motto what would it be?

Live each day as if it were your last.

What is your greatest temptation?

Over-indulging my children.

What is your favourite meal?

Anything cooked by someone else. Although, I am particularly partial to cod, chips and mushy peas at the seaside (I'm easily pleased!)

How do you chill out?

Messing around on the beach with my children whilst hoping I don't bump into anyone I know!

What is your favourite type of music?

Anything 80's. I would be embarrassing myself if I gave any more details.

What is the most important virtue for a scientist?

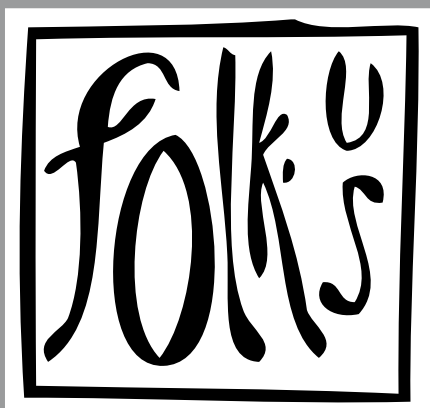
An enquiring mind.

What's your perfect Friday night?

Feet up, gin and tonic, QI on the TV and the children in bed!



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Folk.us receives £100,000

Congratulations are due to Folk.us which has received £100,091 to run until December 31st 2010. Folk.us brings the world of research and researching to people who use health or social care services across Devon.

<http://www.folkus.org.uk>

EVENTS DIARY

25 & 26TH MARCH

PenCLAHRC Learning Together Event

Torquay

Director Stuart Logan has invited everyone who works within PenCLAHRC and a number of our closest collaborators from partner organisations to this event to get together and decide how best to deliver our objectives over the next 3 years.

FRIDAY 16TH APRIL 2010

PENCLAHRC MANAGEMENT BOARD MEETING

FRIDAY 7TH MAY

Next PENCLAHRC lunch

TBC

For those who have not attended before, our regular lunchtime meeting is an opportunity to meet other members of staff involved in the collaboration informally over a buffet lunch.

TUESDAY 11TH MAY

National CLAHRC Directors' meeting Plymouth

MONDAY 17TH MAY 2010

PenCLAHRC Stakeholder Prioritisation Panel Plymouth

**Please save the date! Friday 16th July
PenCLAHRC Learning Development Event
Details to be confirmed**

PenCLAHRC Recent Appointments

- **Victoria Goodwin**
Research Fellow (Primary Care)
- **William Henley**
Senior Lecturer in Medical Statistics
- **Iain Lang**
Consultant in Public Health (a joint appointment with Devon PCT)
- **Jonathan Pinckney**
Clinical Chair in Diabetic Medicine

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The Knowledge Spa, Truro.
PenCLAHRC's work in Cornwall will be examined in issue 5.