



# Use of the **Stroke Patient Concerns Inventory** in **Stroke Outpatient Clinics**

# Background

- A significant proportion of stroke survivors have longer-term ongoing needs
- Half report their needs which are not adequately met by service providers
- Failure to address patient concerns has been linked to:
  - poor self-management
  - poor health outcomes
  - mood disorders
  - increased health care costs

# A patient focused approach

- Traditional consultation – focuses on professional priorities and goals
- May inhibit the patient's ability to express their concerns
- Patient-focused approaches such as motivational interviewing have been linked to improved health outcomes (specialists/training)
- A simple method to help clinicians re-focus the consultation in line with patients' priorities that can be used in a variety of consultation settings is needed.

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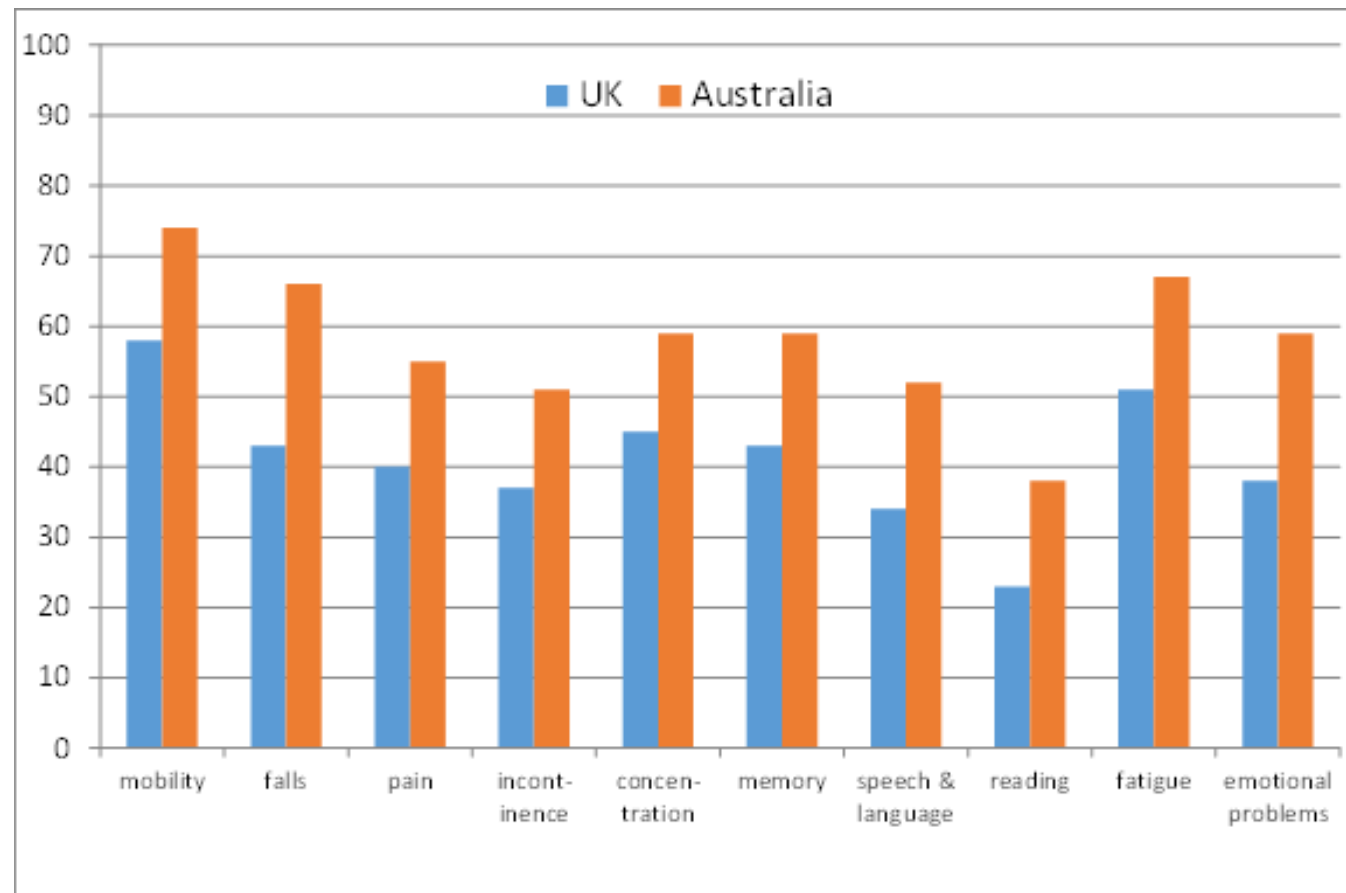
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**What are the three main concerns you think someone might want to discuss in clinic after a stroke**

# Proportion of people with longer-term needs

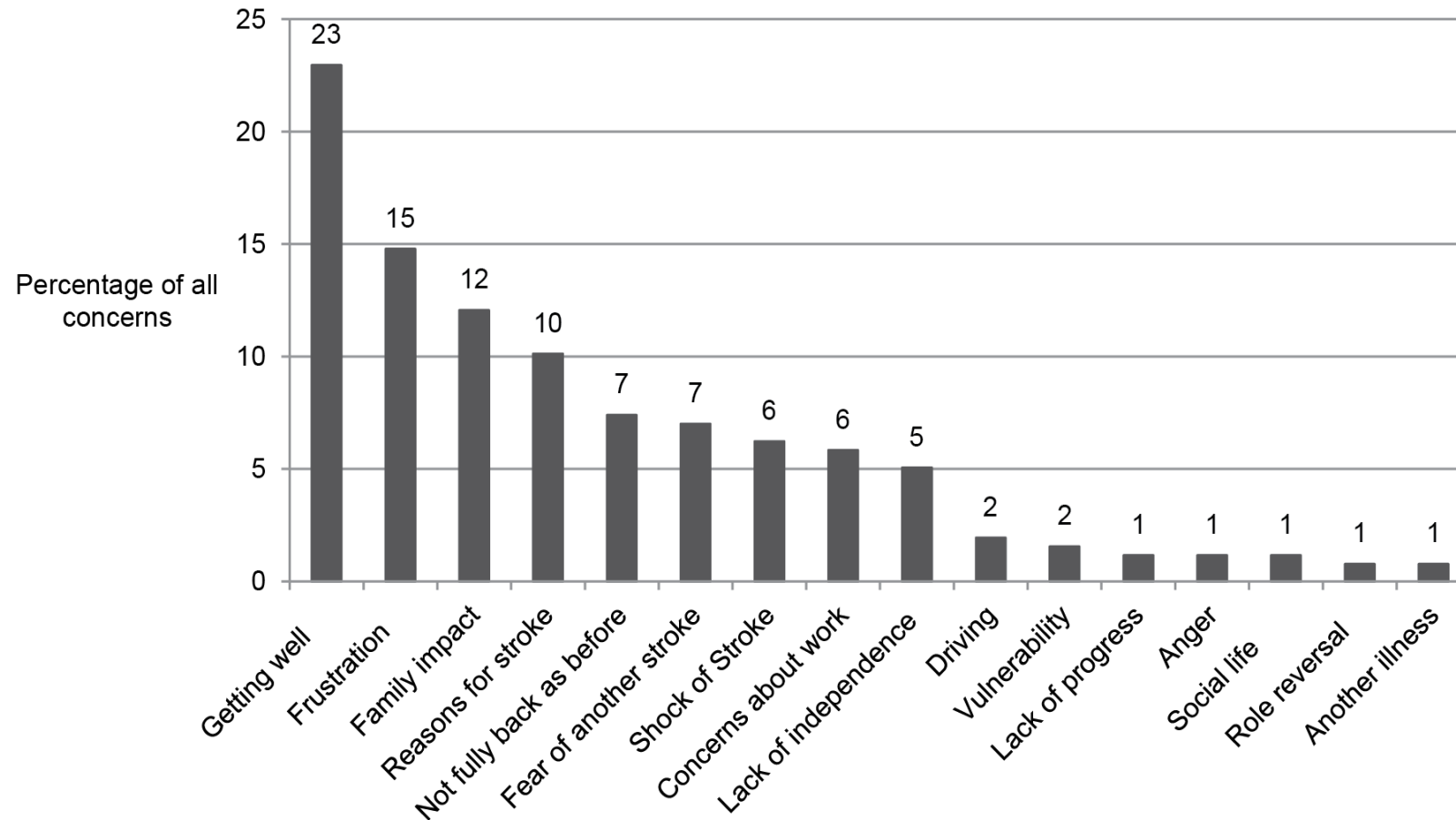


Data taken from the Australian and UK National stroke survivor needs surveys: Andrew et al 2014; McKevitt et al 2011.

# Motivational Interviewing Post-Stroke: An Analysis of Stroke Survivors' Concerns and Adjustment

Qualitative Health Research  
1-9  
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# Patient Concerns Inventory

**[PCI]** Aintree University Hospital NHS Foundation Trust  
Where quality matters

## Head and Neck - After Diagnosis Patient Concerns Inventory [PCI]

The amount of information patients and their family would like after the time of diagnosis of their cancer varies considerably. This Patient Concerns Inventory (PCI) is a checklist to help patients and their family raise issues that they want to talk about with the doctors, nurses and allied health professionals. Tick as many or as few as you wish to help you remember what you want to discuss with our head and neck team.

**Cause of cancer:**

- ☐ Lifestyle issues (smoking/alcohol)
- ☐ HPV
- ☐ Other

**Treatment related:**

- ☐ Investigations needed (MRI/CT)
- ☐ Investigation results
- ☐ Cancer treatment: what choices of treatment are available
- ☐ Treatment intent: cure or palliation
- ☐ Clinical trials - contributing to research
- ☐ Nutrition/feeding tube/PEG
- ☐ What are the side effects/toxicity/complications of treatments
- ☐ Surgery: length of stay in hospital, neck dissection, laser, free flap
- ☐ Radiotherapy: mouth room, number of treatments, sore mouth and skin
- ☐ Chemotherapy: number of treatments, deafness, nausea
- ☐ What is the chance of cure
- ☐ When will I know I am all clear - when will I know treatment has been successful
- ☐ What treatments are available if the cancer comes back

**What will I be like:**

- ☐ How long am I likely to live
- ☐ Waiting time for commencement of treatment
- ☐ Duration of treatment
- ☐ Dental check up

**Follow-up:**

- ☐ What are the main issues that patients find important e.g. speech, swallowing
- ☐ What sort of quality of life do patients report
- ☐ What sort of follow up do I need/how often/ scans/tests
- ☐ Patient and Carer Support Group/meet other patients

**Social care and Social well being:**

- ☐ Care
- ☐ Dependents/children
- ☐ Finance/money
- ☐ Benefits/what's free and what's not
- ☐ Time off work
- ☐ Home care/District nurse
- ☐ Recreation
- ☐ Relationships
- ☐ Speech/voice/being understood
- ☐ Support for my family

Study Number: \_\_\_\_\_  
Date: \_\_\_\_\_

EPRC

Patient Concerns Inventory:  
a prompt-list of  
possible concerns



Before their appointment,  
patients complete the PCI  
in the waiting area \*



The completed PCI  
is provided to the  
healthcare team



The healthcare team use  
the identified concerns to  
guide the consultation



# Stroke Patient Concerns Inventory

PCI

Stroke

## Patient Concerns Inventory [PCI]

Please choose from the list of issues you would specifically like to talk about in your consultation in clinic today. You can choose more than one option (tick boxes).

### Physical and functional well-being:

- ☐ Aids/Adaptations
- ☐ Alcohol
- ☐ Altered taste
- ☐ Balance/Dizziness
- ☐ Continence
- ☐ Diet
- ☐ Eating/Drinking/Swallowing
- ☐ Exercise
- ☐ Falls/Accidents
- ☐ Fits/Seizures
- ☐ Hand/Arm movement
- ☐ Headaches
- ☐ Mouth care
- ☐ Muscle spasms/stiffness
- ☐ Pain
- ☐ Pregnancy
- ☐ Recovery
- ☐ Sensation/Feeling
- ☐ Sex
- ☐ Smoking
- ☐ Tiredness/Energy
- ☐ Vision
- ☐ Walking
- ☐ Weight

### Treatment related:

- ☐ Medication
- ☐ Risk of another stroke
- ☐ Tests
- ☐ Therapy

### Psychological, emotional and spiritual well-being:

- ☐ Anxiety/Fear
- ☐ Behaviour/personality
- ☐ Confidence/Self-esteem
- ☐ Coping
- ☐ Emotions (anger/crying/laughing inappropriately)
- ☐ Loneliness/Isolation
- ☐ Low mood
- ☐ Sleep
- ☐ Thinking (memory/numbers/understanding/concentration)

### Social care and social well-being:

- ☐ Accommodation
- ☐ Children/Dependants
- ☐ Driving/Finances/Benefit advice
- ☐ Hearing
- ☐ Housework
- ☐ Independence
- ☐ Legal concerns
- ☐ Personal care (washing/dressing)
- ☐ Reading/Writing
- ☐ Relationships (Family/Friends)
- ☐ Return to work/hobbies
- ☐ Shopping
- ☐ Support for carers
- ☐ Talking/Communication
- ☐ Transport/Travel

### Others (please state):

.....

.....

.....

NHS number:

Date:

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sheet 2/2

The following page lists people you may wish to talk to. Some of these people may be available in clinic, otherwise it may be possible to refer you to them. Are there any people you would specifically like to talk with?

### Physical and functional well-being:

- ☐ Audiologist
- ☐ Dentist/Dental hygienist
- ☐ Dietitian
- ☐ Nurse
- ☐ Occupational Therapist
- ☐ Orthoptist/Optician
- ☐ Physiotherapist
- ☐ Speech and Language Therapist (for communication/swallowing problems)

### Psychological, emotional and spiritual well-being:

- ☐ Counsellor
- ☐ Psychologist
- ☐ Spiritual/Religious leader

### Treatment related:

- ☐ Stroke Doctor
- ☐ Stroke Specialist Nurse

### Social care and social well-being:

- ☐ Agencies that support carers
- ☐ Financial advisor/Citizens Advice
- ☐ General practitioner
- ☐ Peer/Support groups
- ☐ Primary care (e.g. GP/Nurse)
- ☐ Social worker
- ☐ Stroke Association

### Others (please state):

.....

.....

Thank you for your time. All information is confidential. We hope that the PCI will help you express any concerns or issues in your clinic appointment.

The Stroke PCI was developed by the University of Central Lancashire in collaboration with Edge Hill University (EHU) and Aintree University Hospital NHS Foundation Trust (AUH). It uses the Patient Concerns Inventory (PCI) framework developed by EHU and AUH.

NHS number:

Date:

PCI

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Two pages:

1. List of **concerns** categorised into
  - Physical and functional well-being
  - Treatment related
  - Psychological, emotional and spiritual well-being
  - Social care and social well-being
2. List of health and social care **professionals**

> J Stroke Cerebrovasc Dis. 2023 Jun;32(6):107053. doi: 10.1016/j.jstrokecerebrovasdis.2023.107053. Epub 2023 Mar 21.

### Development of the stroke patient concerns inventory: A modified Delphi study

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# NIHR RfPB Award

*Use of the Stroke Patient Concerns Inventory (sPCI) in stroke outpatients clinics: a feasibility cluster randomised controlled trial.*  
Patel K, Lightbody CE, Watkins C, Rogers S, Prescott G, Clegg A, Benedetto V, Gibbon B, Kontou E, Gordon C, Gaskins N.  
NIHR RfPB. Awarded £249,708. 2024

## Aim

To explore the **feasibility** and **acceptability** of conducting a definitive cluster randomised controlled trial (RCT) to evaluate the effectiveness and cost-effectiveness of the sPCI

## Objectives

- Do patients and staff **use** the sPCI?
- Is the sPCI **acceptable** to patients and staff?
- What are the **barriers/facilitators** for using the sPCI?
- How appropriate are the **outcome** measures?
- What proportion of eligible patients **participate** and complete the trial?
- What proportion of **data** is complete?

# NIHR RfPB Award

## Feasibility cluster randomised controlled trial

