

How would a Stroke Patient Concerns Inventory be implemented in practice? A qualitative study

Kulsum Patel¹, Lorna Fazackerley², Nicola Gaskins¹, Stephanie Jones¹, Catherine Elizabeth Lightbody^{1,2}

¹University of Central Lancashire; ²Lancashire Teaching Hospitals NHS Foundation Trust

INTRODUCTION

Stroke survivors experience a range of ongoing physical, psychological and social **concerns** affecting quality of life¹. Despite strategies and recommendations for post-stroke care^{2,3}, there is a **lack of systems and tools** that allow healthcare professionals to identify stroke survivors' concerns and so they are often **not adequately addressed**.

Review appointments are time-limited, reducing opportunity for patients to discuss, and healthcare staff to identify, concerns. A **structured approach** to identify concerns during consultations, the Patient Concerns Inventory (PCI)⁴, has proved successful in oncology.

The PCI has been adapted for use with stroke survivors (Stroke PCI (sPCI); figure 1). **We explored healthcare staff and patient/carer views on the potential use of the sPCI in practice.**

METHODS

STAFF: Semi-structured individual **interviews** (n=12) underpinned by the Theoretical Domains Framework⁵ (TDF) with staff from **one stroke multidisciplinary team** (MDT) in an acute hospital NHS Trust in North West England. Purposive sampling ensured representation from **various staff grades and disciplines**.

One researcher (occupational therapist from the MDT) conducted interviews, and with an independent researcher carried out **thematic analysis**: coding based on TDF domains and then theme identification.

PATIENTS/CARERS: Two **focus groups** (n=8 (3 stroke survivors, 5 carers); n=3 (2 stroke survivors, 1 carer)) and semi-structured individual **interviews** (n=2 stroke survivors) with participants from across England, conducted by two researchers, analysed thematically.

FINDINGS

[PCI]

sheet 1/2

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).

<p>Physical and functional well-being:</p> <input type="checkbox"/> Aids/Adaptations <input type="checkbox"/> Alcohol <input type="checkbox"/> Altered taste <input type="checkbox"/> Balance/Dizziness <input type="checkbox"/> Continence <input type="checkbox"/> Diet <input type="checkbox"/> Eating/Drinking/Swallowing <input type="checkbox"/> Exercise <input type="checkbox"/> Falls/Accidents <input type="checkbox"/> Fits/Seizures <input type="checkbox"/> Hand/Arm movement <input type="checkbox"/> Headaches <input type="checkbox"/> Mouth care <input type="checkbox"/> Muscle spasms/stiffness <input type="checkbox"/> Pain <input type="checkbox"/> Pregnancy <input type="checkbox"/> Recovery <input type="checkbox"/> Sensation/Feeling <input type="checkbox"/> Sex <input type="checkbox"/> Smoking <input type="checkbox"/> Tiredness/Energy <input type="checkbox"/> Vision <input type="checkbox"/> Walking <input type="checkbox"/> Weight	<p>Treatment related:</p> <input type="checkbox"/> Medication <input type="checkbox"/> Risk of another stroke <input type="checkbox"/> Tests <input type="checkbox"/> Therapy <p>Psychological, emotional and spiritual well-being:</p> <input type="checkbox"/> Anxiety/Fear <input type="checkbox"/> Behaviour/personality <input type="checkbox"/> Confidence/Self-esteem <input type="checkbox"/> Coping <input type="checkbox"/> Emotions (anger/crying/laughing inappropriately) <input type="checkbox"/> Loneliness/Isolation <input type="checkbox"/> Low mood <input type="checkbox"/> Sleep <input type="checkbox"/> Thinking (memory/numbers/understanding/concentration)	<p>Social care and social well-being:</p> <input type="checkbox"/> Accommodation <input type="checkbox"/> Children/Dependants <input type="checkbox"/> Driving <input type="checkbox"/> Finances/Benefit advice <input type="checkbox"/> Hearing <input type="checkbox"/> Housework <input type="checkbox"/> Independence <input type="checkbox"/> Legal concerns <input type="checkbox"/> Personal care (washing/dressing) <input type="checkbox"/> Reading/Writing <input type="checkbox"/> Relationships (family/friends) <input type="checkbox"/> Return to work/hobbies <input type="checkbox"/> Shopping <input type="checkbox"/> Support for carers <input type="checkbox"/> Talking/Communication <input type="checkbox"/> Transport/Travel <p>Others (please state):</p> <p>_____</p> <p>_____</p> <p>_____</p>
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NHS number: _____
Date: _____

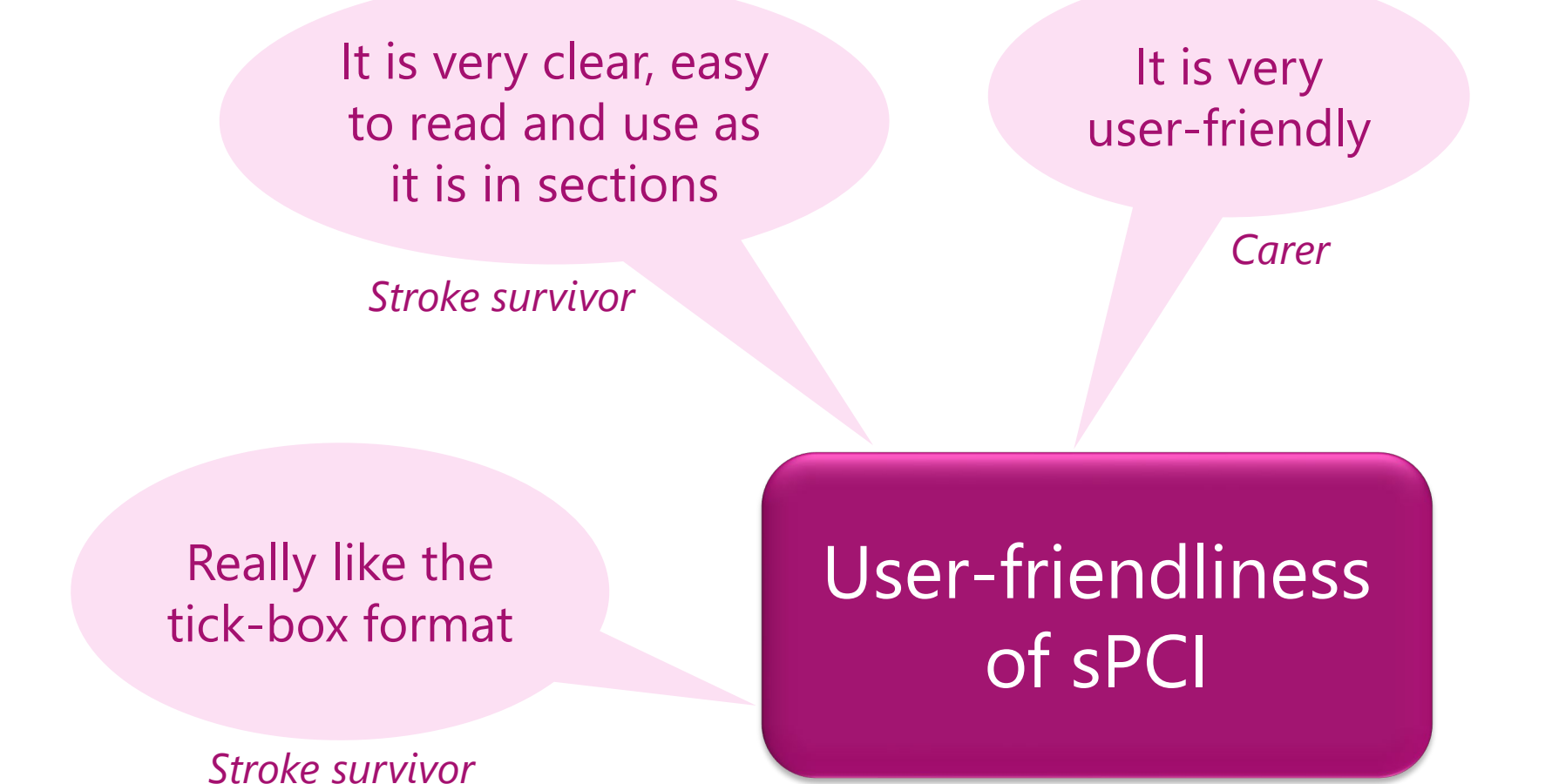
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- 12 staff participants:
- Nurses
 - Clinical psychologist
 - Medical registrar
 - Speech & language therapist
 - Occupational therapist
 - Therapy assistant
 - Physiotherapists

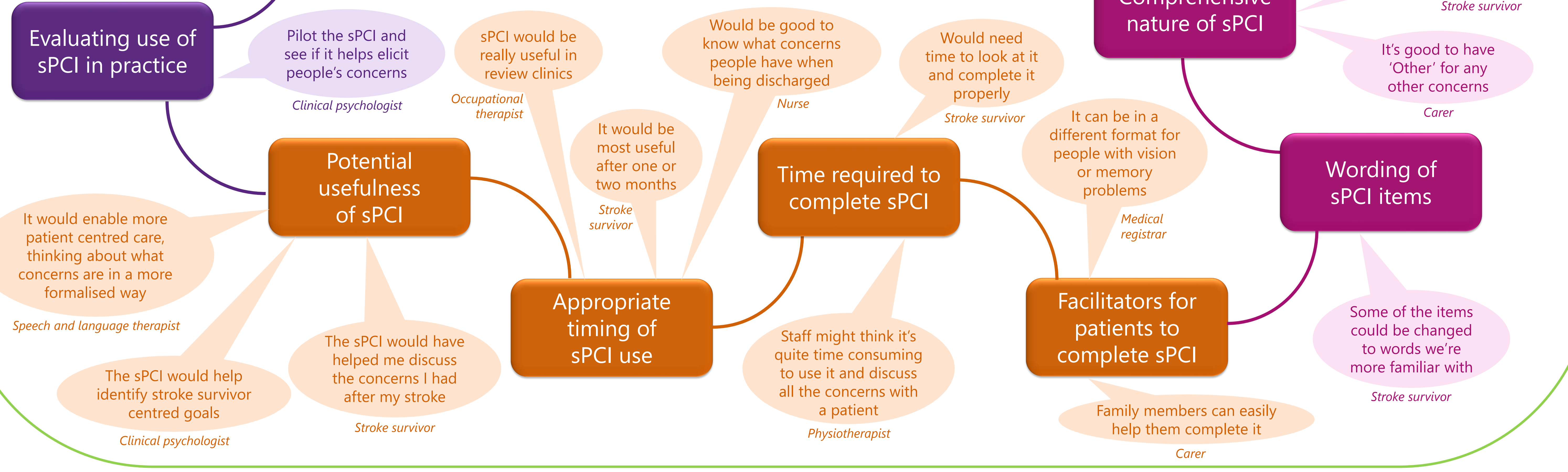
- 13 patient/carer participants:
- Stroke survivors
 - Carers

STAFF PARTICIPANT THEMES

PATIENT/CARER PARTICIPANT THEMES



OVERLAPPING STAFF & PATIENT/CARER PARTICIPANT THEMES



CONCLUSIONS

Staff, stroke survivors and carers deemed the sPCI to be potentially **useful** for enhancing the **identification and discussion** of concerns after stroke **along the care pathway**. Implementing the sPCI in practice will require consideration of appropriate **wording, when it is used**, ensuring it is available in alternative **formats** to increase accessibility, and ensuring staff and services are **equipped** to address raised concerns.

NEXT STEPS

Planning a **feasibility study** to explore the feasibility and acceptability of conducting a definitive trial to evaluate the **effectiveness** and cost-effectiveness of the sPCI.

CONTACT:
Kulsum Patel
kpatel@uclan.ac.uk

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