Improving the lives of stroke survivors with data

Stakeholder Engagement Group Meeting

Tuesday 4th April 2023

Welcome and introductions

At our next Stakeholder Engagement Group meeting we will:

- Update you on research progress

- Discuss the patient portal

- Ask you to help us identify what information and tools we should add to version 1 of our patient portal

Since our last meeting:

- **Drafted systematic literature review** (informal cost of care)

- Drafted a paper based on interviews with patients on the **informal costs of stroke care**

- **Ran 2 workshops with stroke survivors** on how we can **better involve stroke survivors with communication difficulties in Patient and Public Involvement (PPI) and research**

Since our last meeting:

- **Establish a new cohort of ICD-11 patients** -Understand the incidence and outcomes of the new definition

- **Analysed established database of >7500 enrolled patients**- Understand long term changes in patient health

- Designed and produced a **portal prototype** with basic functionality

South London Stroke Register (SLSR)

The study is linked to the South London Stroke Register (SLSR), an ongoing population-based register recording first stroke in patients of all age groups in Lambeth and Southwark, inner-city South London since 1995.

Collecting and analysing data from the SLSR forms a core part of the programme (Work Package 2). In the next five years, our focus will be on understanding the impact of changes in how stroke is defined (the ICD-11 definition, which better recognises milder stroke), and on the longitudinal outcomes and care needs of stroke survivors.

What is a Portal for Stroke Survivors?

A patient portal is a secure website or mobile application that allows patients to access and manage their health records, and their own health.

Our portal will initially:

- Provide access to the stroke survivors' answers to SLSR questions

Portals can also:

- **promote communication** between stroke patients, healthcare providers, research teams, and the community. The research team can also better understand patients' health progress over time

- **empower patients** to actively manage their health to better understand disease recovery and health progress, with *improved patient decision-making*

Health Information Collected in SLSR Questionnaires

Patient journey with SLSR

Entry	Date	Hospital
Initial SLSR questionnaire (within 2 weeks of stroke)	15/02/2015	St Thomas'
3 month follow up	20/05/2015	N/A
1 year follow up	18/02/2015	N/A

Risk factors

- Hypertension
- Congestive cardiac failure
- Angina
- Hypercholesterolaemia

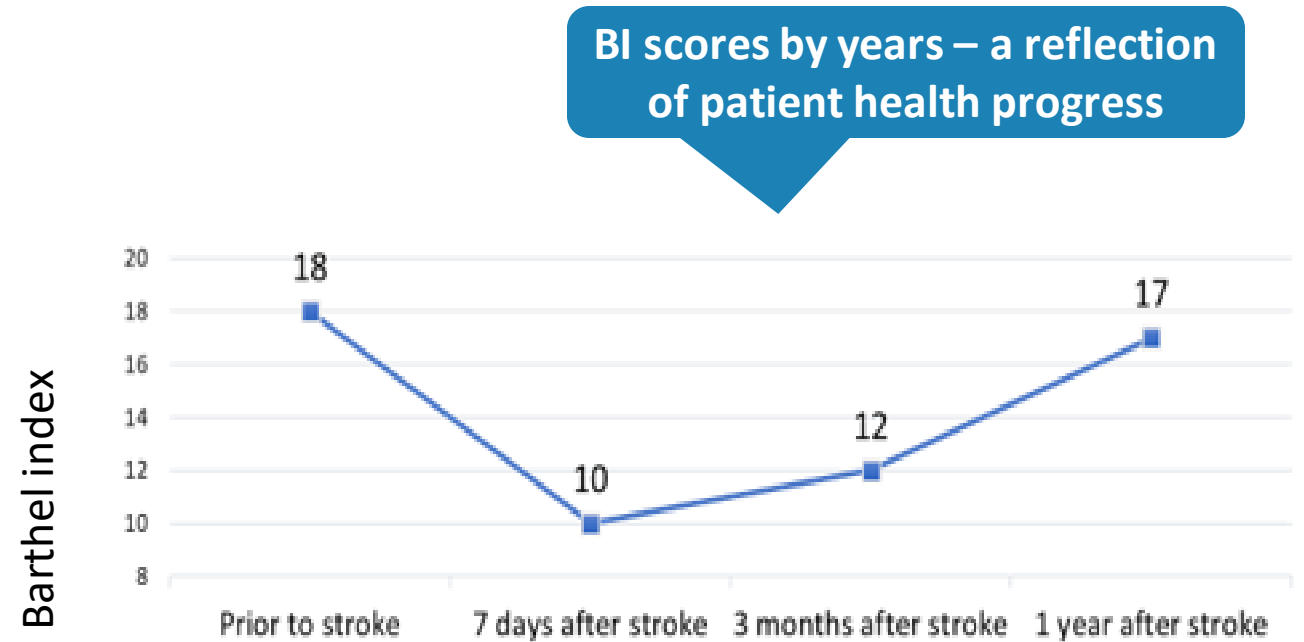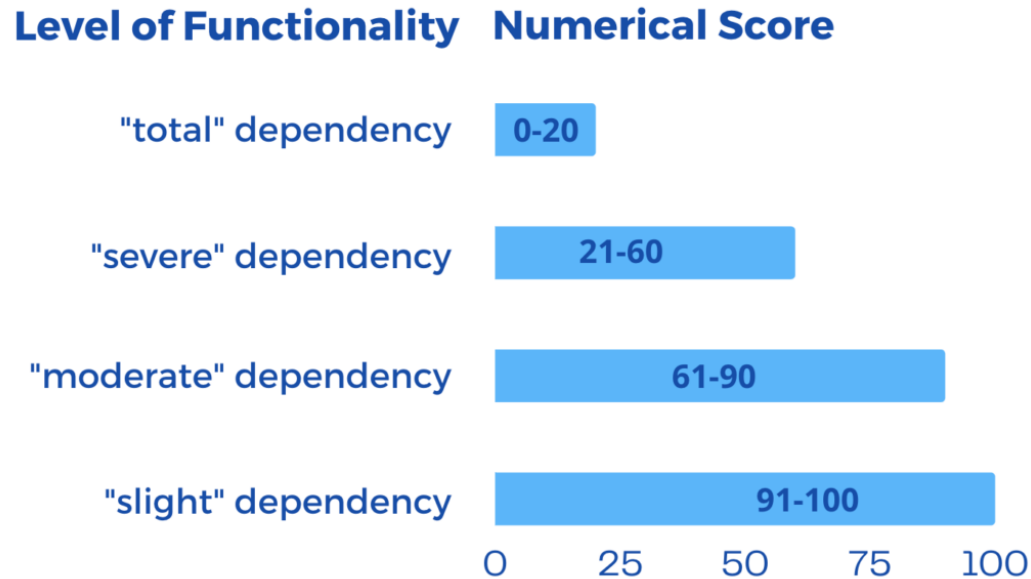**Medications**

- Aspirin
- Warfarin
- Clopidogrel
- AntiDiabetics

Giving patients access to the records we hold will enable them to have information from the different questionnaires they have completed. This will also enable some of the standardised scales we ask patients to complete at different time points (such as the Barthel Index) to be presented back to the stroke survivor.

Presenting Standard Scales in the Portal

The Barthel Scale/Index (BI) is an ordinal scale used to measure performance in activities of daily living

Level of Functionality | **Numerical Score**

"total" dependency — 0-20

"severe" dependency — 21-60

"moderate" dependency — 61-90

"slight" dependency — 91-100

BI scores by years – a reflection of patient health progress

Barthel index

| Prior to stroke | 7 days after stroke | 3 months after stroke | 1 year after stroke |

18 · 10 · 12 · 17

This is only one example of how we use patients' data. We are going to start a big piece of work in making sure that we present these data in a way which is *understandable, useful and assessable*.

Key Potential Features and Functions

Additional functions features we could add to a patient portal for stroke survivors

Access health information

VIEW HEALTH RECORDS

View and download your personal medical documents. Share your data with your care givers or family members.

COMMUNICATE WITH COMMUNITY

Send and receive messages to stay in touch with your health provider and local community. Ask questions to AI-powered interactive chatbox

Efficient communication

Health information upload

UPLOAD PERSONAL VITAL SIGNS

Regularly monitor and share your vital signs and health conditions with your health providers on a cloud-based secured SLSR databse

VIEW and TRACK YOUR HEALTH

Check and understand what your measured vital signs tell you about your health conditions. We will help you understand your data and give appropriate advice to make you feel better

Data interpretation

Carer giver support

CARER GIVER HELP CENTRE

Help carer giver to monitor their health conditions and offer supports to carer givers, such as education, training, emotional support with facilitated communication

EDUCATIONAL RESOURCES

Help carer giver to monitor their health conditions and offer supports to carer givers, such as education, training, emotional support with facilitated communication

Education resources

Questions

In our SEG meeting, there will be a demonstration of the current (early stage) version of the portal. We would value your feedback on this version and like to discuss the following questions with you:

1. What are the most important features that patients and clinicians need in a patient portal?

2. How can we ensure that the patient portal is user-friendly and easy to navigate?

3. In what ways do you think a patient portal could improve patients' healthcare experience and outcome?

Key Terms and Definitions

Barthel Index – is an ordinal scale used to measure performance in activities of daily living (ADL). e.g. Barthel index score = 22, it means the patient has a "severe" dependency

NIH STROKE SCALE (NIHSS) - Scoring tool applied to record severity of stroke experienced by patient

EQ-5D-5L – Questionnaire on quality of life considers five components e.g. mobility, self-care, daily activities, pain and anxiety/depression

SF-12 - Self-reported measure considering relationship between health impact and everyday life of individual