KING'S College LONDON

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SLSR
SOUTH LONDON STROKE REGISTER

NHS
Guy's and St Thomas'
NHS Foundation Trust

IMPROVING THE LIVES OF STROKE SURVIVORS WITH DATA

Stakeholder Engagement Group

31 October 2023

Key points

- Key findings/outputs from each Work Package
- Discuss plans for Y3, 4, 5 regarding checkpoint report due 31st December 2023

Recap/summary of progress

- Start date 1st January 2022 (1 year 8 months)
- WP1 – on schedule
- WP2
  - recruited RA September 2022
  - new protocol signed and started April 2022
- WP3
  - Recruited RA September 2022
  - Input from WP1, and initial version of portal completed

Progress in numbers

Since 1st January 2022 we have achieved:

- 14 patient meetings, 2 public meetings, 4 stakeholder meetings, 1 policy lab
- 544 participants recruited for South London Stroke Register
- 16 conference abstracts/workshop papers, 11 posters
- 9 publications

Checkpoint/next steps 1.

Overall, the committee welcomed the proposal; however, work package (WP) 3 was viewed as the least compelling component. There remained concerns about the:

- Lack of methodological detail
- reach into the general population
- potential benefits from multiple small feasibility studies
- extent to which health literacy had been addressed, specifically the ability of users to engage with the portal, particularly those who had suffered a stroke
- degree to which social science and qualitative methods were being used to inform and understand the portals, and patient experience of their use and,
- sustainability of the portal beyond the duration of the programme

Checkpoint/next steps 2.

- Checkpoint report due 31st December
- Substantially revise plans for WP3 development and evaluation
  - Show how results from qualitative work/policy labs/stakeholders are feeding into development
  - Currently showing data, priorities for models (recurrence of stroke, and recovery trajectories)

WP1 — Preliminary findings from the first Policy Lab

The Policy Lab brought together a range of stakeholders to consider where there is **untapped potential in stroke data and data-driven innovation**.

A series of sessions considered:

- **Challenges** in the use of data
- A **vision** for stroke data and **changes needed** to realise this at national, ICS, organisational and individual patient levels.
- **Actions** that could help improve care and outcomes for stroke survivors

Proposed actions were prioritised and four were developed in further detail:

- Collecting patient-generated longitudinal data
- Using existing data to develop risk profiles for stroke survivors
- Accessible, timely and compelling data dissemination and communication of the ‘story’
- Using data to promote collaboration between integrated care systems on low-volume interventions

Findings are being written up as a message-led briefing document.

WP1.3 — Preliminary findings from stroke survivor and carer interviews

- These interviews were designed to elicit practical ways we can refine the portal design to meet stroke survivor and carer needs. Participants requested that the portal provides:

- Interviews with other stakeholders (including clinicians, AHPs, and researchers) are planned for early next year.

Access via their mobile phone with an easy log in process.

Audio options to allow written text to be read out to them (key for those with aphasia)

Methods to share experiences with other stroke survivors.

The ability to monitor not only activities of daily living but also aspects of mental health and emotions as well as things like headaches.

Resources for stroke survivors and carers e.g. videos, information on support and care available, local groups and resources to help educate family members on stroke.

WP1 — Programme Development Grant

Equitable and Inclusive Patient and Public Involvement in Stroke Research (EquIPS)

£150,000, March 2024 - February 2026

Question:

How can we support the involvement of all stroke survivors in patient and public involvement activities?

Aims:

To develop best practice in inclusive stroke patient and public involvement.

To coproduce digital and face to face methods of facilitating the participation of all stroke survivors in patient and public involvement activities.

To pilot, evaluate, refine and disseminate new methods and tools of patient and public involvement that facilitate the involvement of all stroke survivors.

To develop a network of stroke patient and public involvement professionals to share knowledge on inclusive involvement.

WP1 — Next 3 years

WP1.3 - Complete and analyse interviews with other stakeholders (including clinicians, AHPs, and researchers) are planned for early next year.

Continue to support WP3 with the development of the portal and Stakeholder Dashboard.

Develop the evaluation framework for our engagement evaluation activities, and complete evaluation.

Use findings from WP1.2 (informal cost of care), to help refine, validate and pilot new questions for South London Stroke Register.

Disseminate findings, both in academic forums (i.e. articles and presentations) as well as through different PPI Groups nationally, public fora, blogs and other freely accessible means.

Develop on programme work through further grants (RfPB, HSDR, ESRC) and complete the Programme Development Grant.

WP2 — SLSR Recruitment

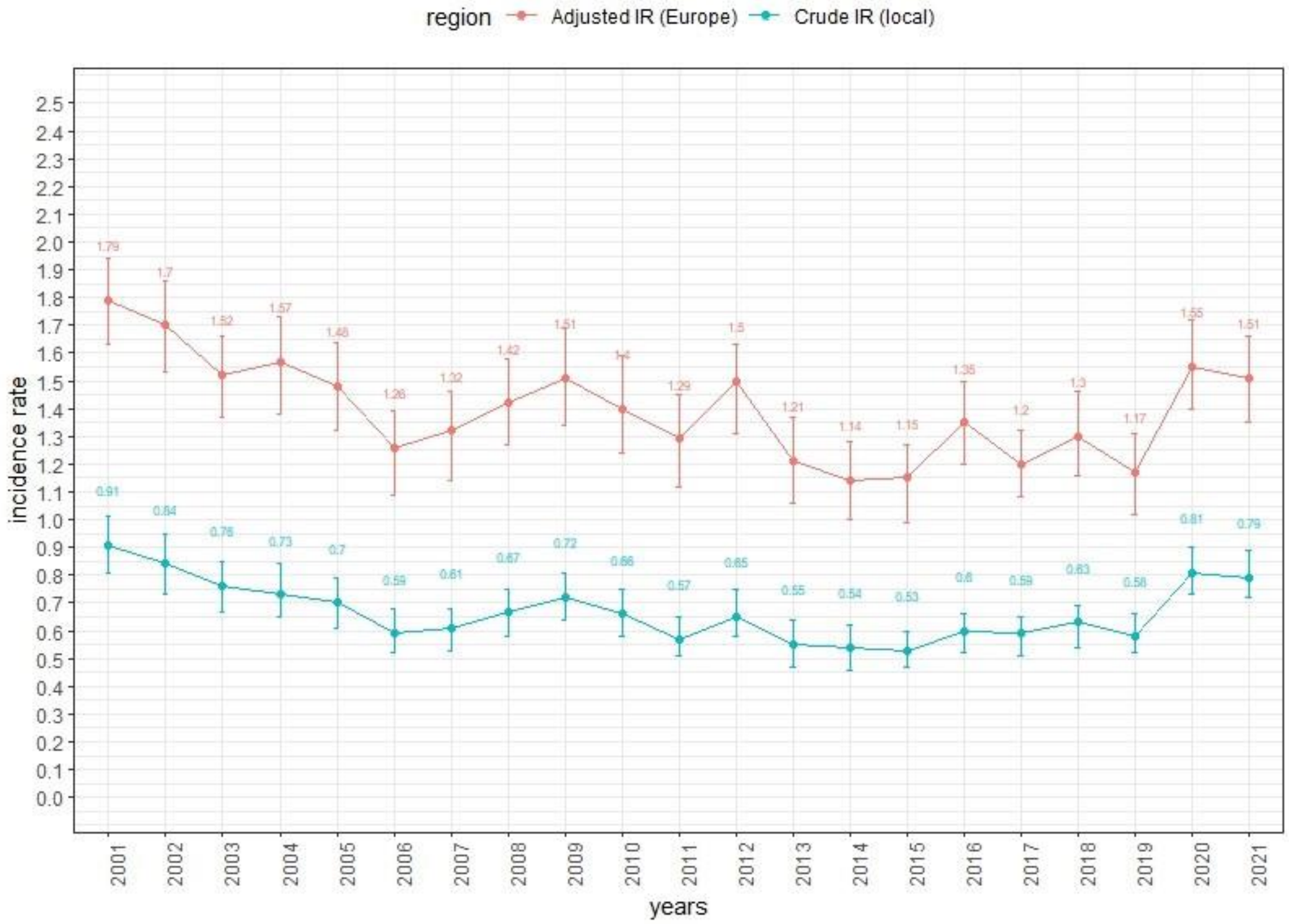
South London Register Recruitment

Total since inception
N=8270 (to 26/10/23)

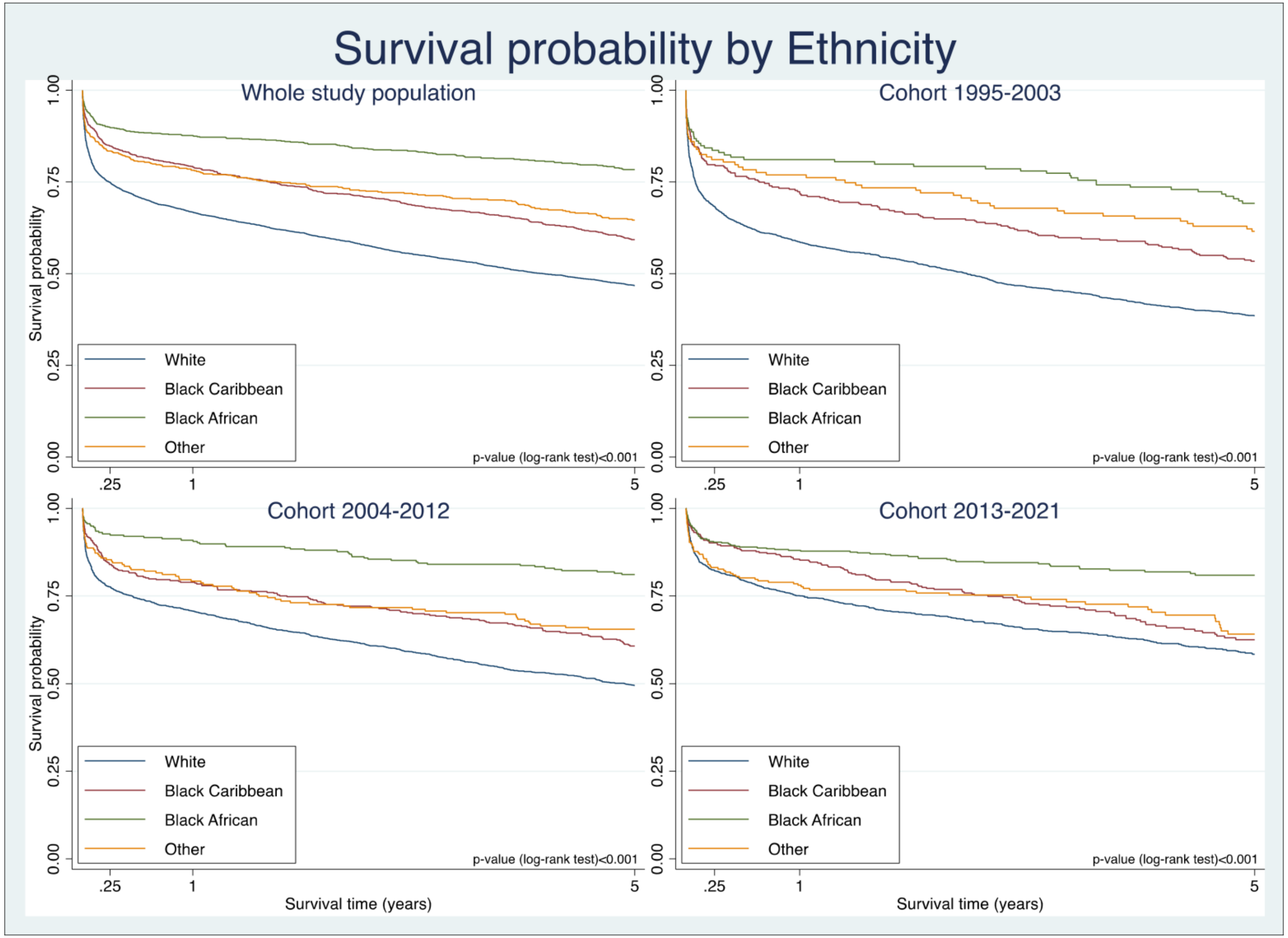
New protocol since April 2022
544 (to 26/10/23)

New ICD-11 cases (scan positive with <24hr symptoms)
22 (to 07/23)
16 in 2022 (April to Dec)
6 in 2023 (Jan to July)

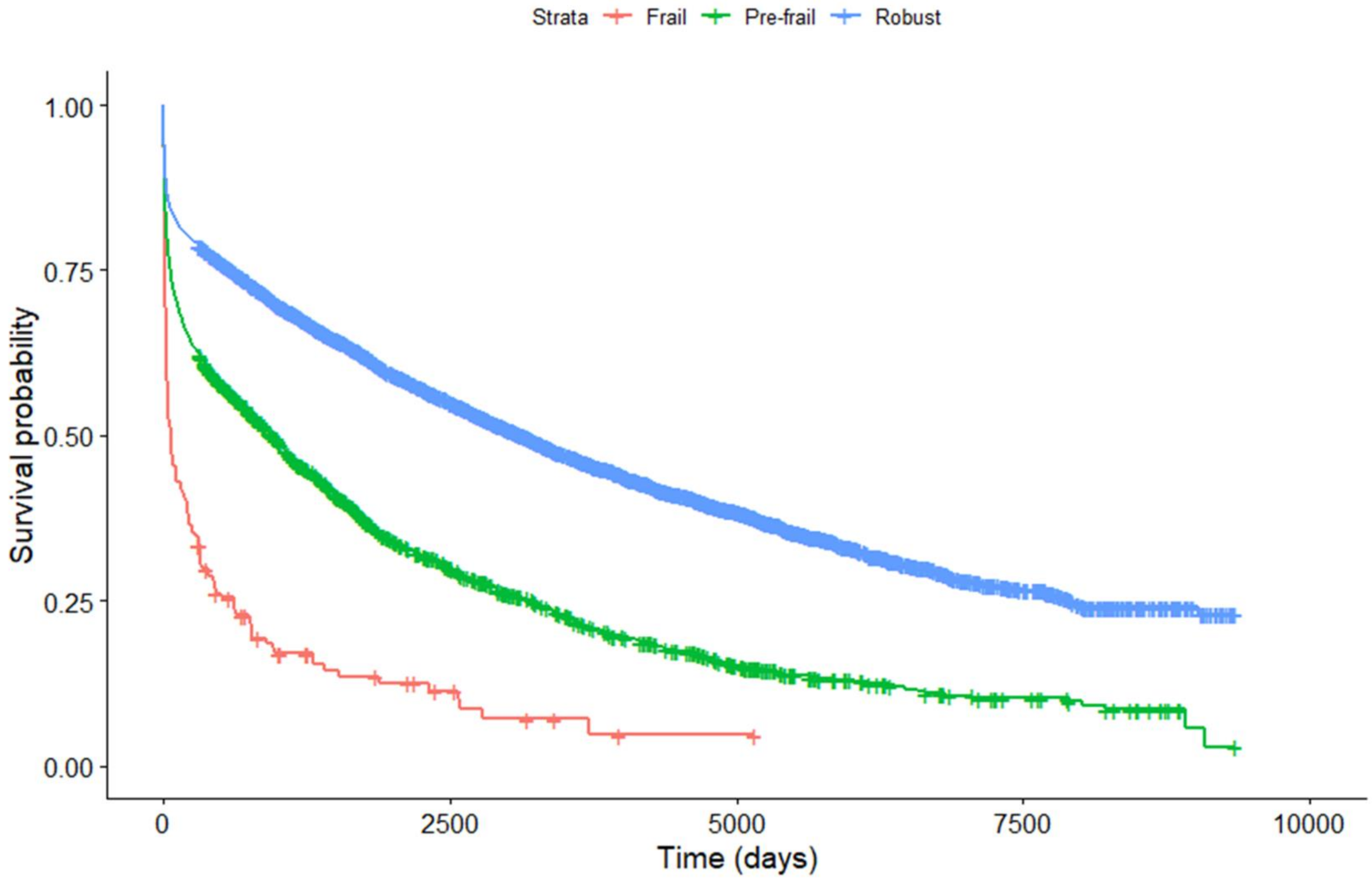
WP2 — Preliminary results - 20-year incidence trends



WP2 — Preliminary results – Ethnicity & survival



WP2 — Preliminary results – stroke frailty index



Initial version of pre-stroke stroke-frailty index stratifies mortality risk across patients

WP3.1 — Patient Portal: Key Progress & Outputs

KEY PROGRESS

- **Milestone 1**: Collated basic user needs & completed system requirement specification;
- **Milestone 2**: High-fidelity UX design and porotype;
- **Milestone 3**: Functional patient portal (Java Web Server) connected with synthetic SLSR database

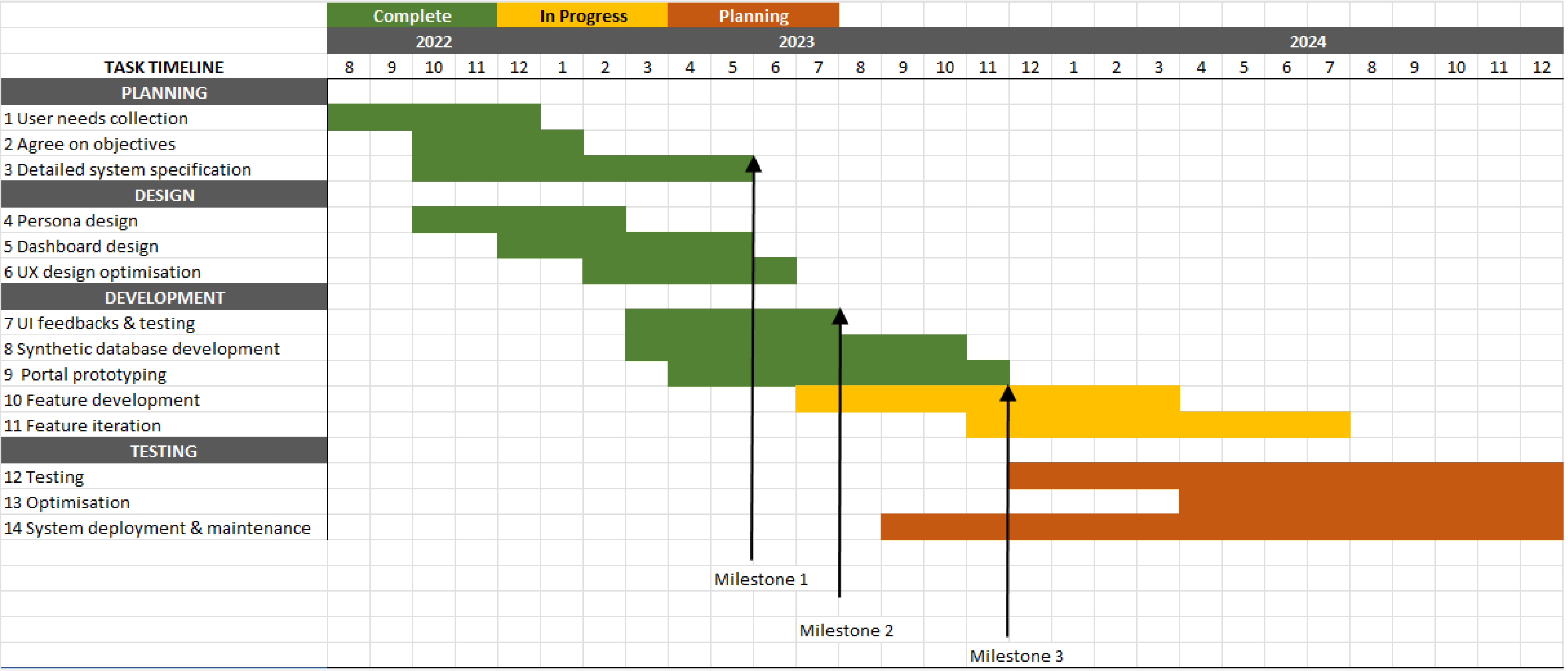


Figure 1. Key timeline and milestones of WP3 research work.

KEY OUTPUTS

Design
- 1 UX prototype
- 1 UX site map
- 3 UX personas

System development
- 1 system requirement specification
- 1 synthetic SLSR database
- 1 portal user database
- 1 Java web system (patient portal)

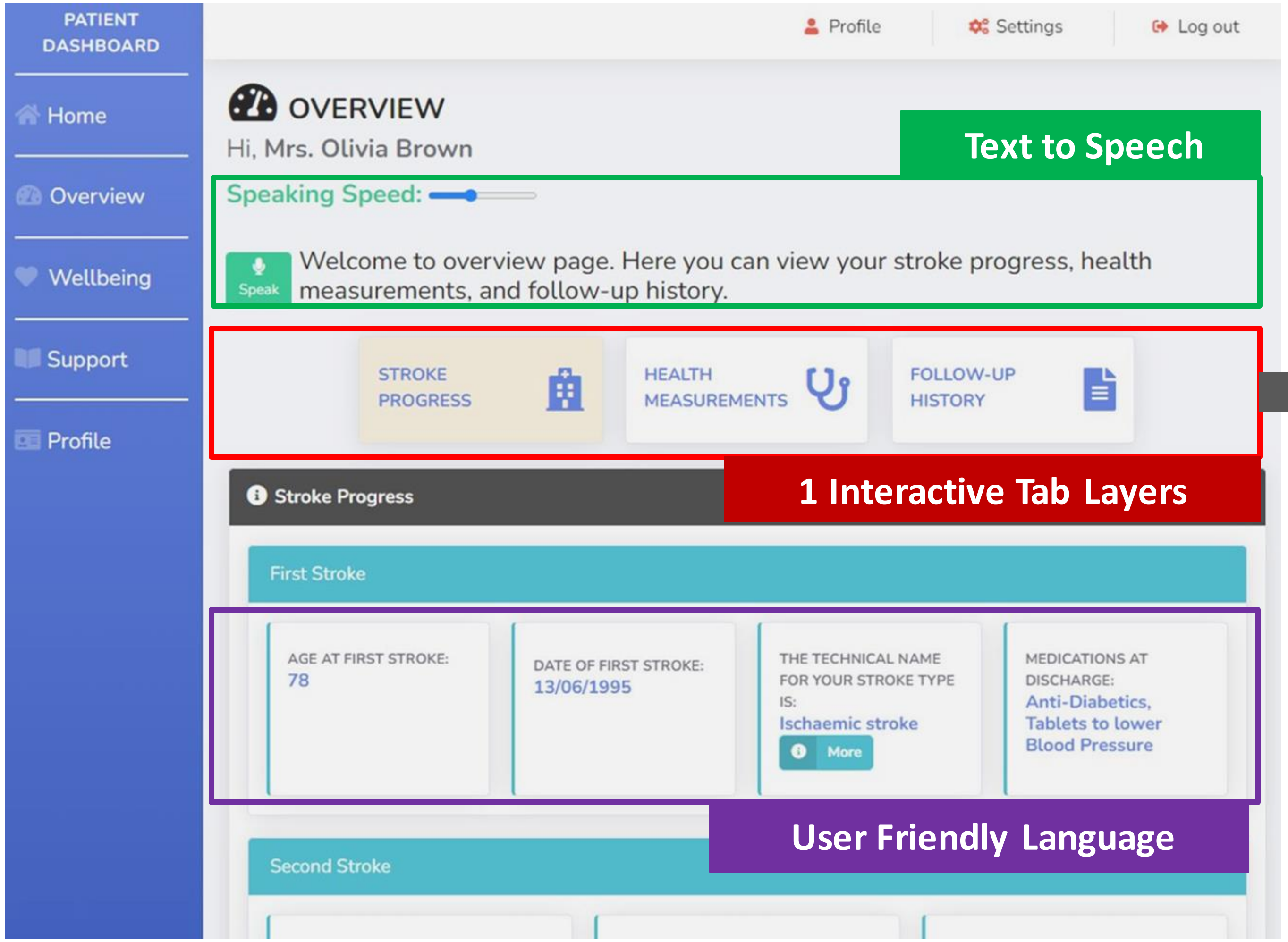
Publications
- 1 workshop paper (CHI 2023)
- 1 position paper (CHI 2023)
- 1 abstract （UKSF23）

Work in progress
- System iteration & optimization
- Conference paper (ICHI 2024)

WP3.1 — Functional Patient Portal (1/3)

SNAPSHOTS

DASHBOARD – New layouts and Text to Speech



OVERVIEW

Hi, Mrs. Olivia Brown

Speaking Speed:

Welcome to overview page. Here you can view your stroke progress, health measurements, and follow-up history.

Stroke Progress

First Stroke

AGE AT FIRST STROKE: 78

DATE OF FIRST STROKE: 13/06/1995

THE TECHNICAL NAME FOR YOUR STROKE TYPE IS: Ischaemic stroke

MEDICATIONS AT DISCHARGE: Anti-Diabetics, Tablets to lower Blood Pressure

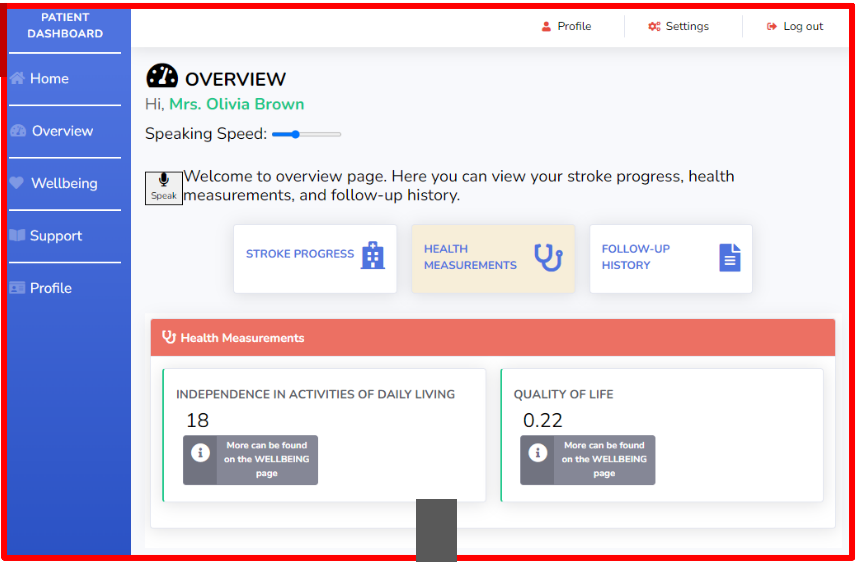
Second Stroke

Text to Speech

1 Interactive Tab Layers

User Friendly Language

2



OVERVIEW

Hi, Mrs. Olivia Brown

Speaking Speed:

Welcome to overview page. Here you can view your stroke progress, health measurements, and follow-up history.

Health Measurements

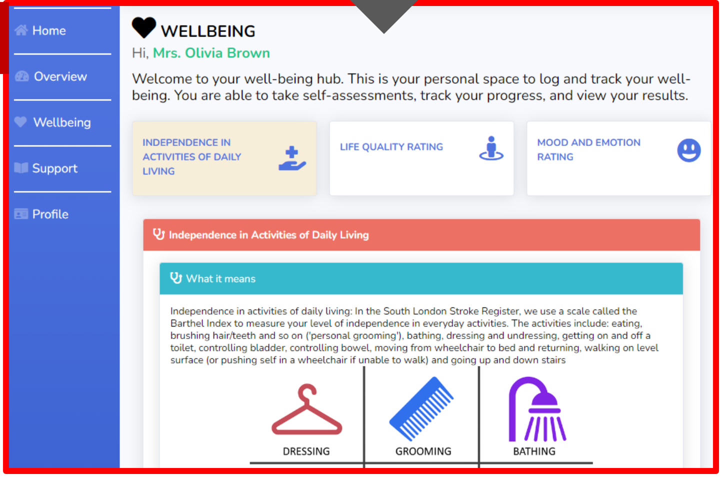
INDEPENDENCE IN ACTIVITIES OF DAILY LIVING: 18

More can be found on the WELLBEING page

QUALITY OF LIFE: 0.22

More can be found on the WELLBEING page

3



WELLBEING

Hi, Mrs. Olivia Brown

Welcome to your well-being hub. This is your personal space to log and track your well-being. You are able to take self-assessments, track your progress, and view your results.

Independence in Activities of Daily Living

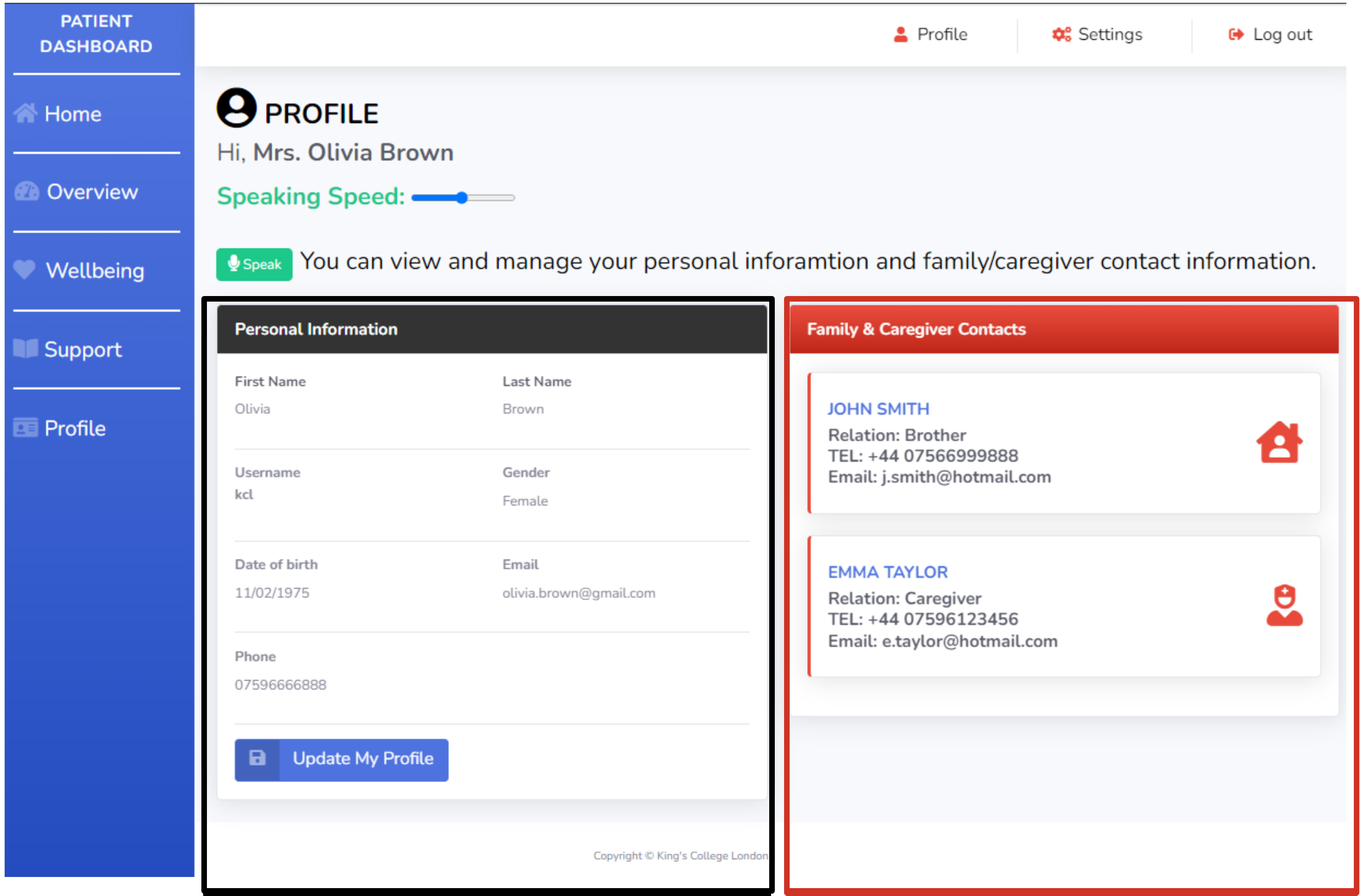
What it means

Independence in activities of daily living: In the South London Stroke Register, we use a scale called the Barthel Index to measure your level of independence in everyday activities. The activities include: eating, brushing hair/teeth and so on ('personal grooming'), bathing, dressing and undressing, getting on and off a toilet, controlling bladder, controlling bowel, moving from wheelchair to bed and returning, walking on level surface (or pushing self in a wheelchair if unable to walk) and going up and down stairs

WP3.1 — Functional Patient Portal (2/3)

SNAPSHOTS

PROFILE – Family & Caregiver Contacts



PROFILE

Hi, Mrs. Olivia Brown

Speaking Speed:

You can view and manage your personal inforamtion and family/caregiver contact information.

Personal Information

First Name: Olivia
Last Name: Brown
Username: kcl
Gender: Female
Date of birth: 11/02/1975
Email: olivia.brown@gmail.com
Phone: 07596666888

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Family & Caregiver Contacts

JOHN SMITH
Relation: Brother
TEL: +44 07566999888
Email: j.smith@hotmail.com

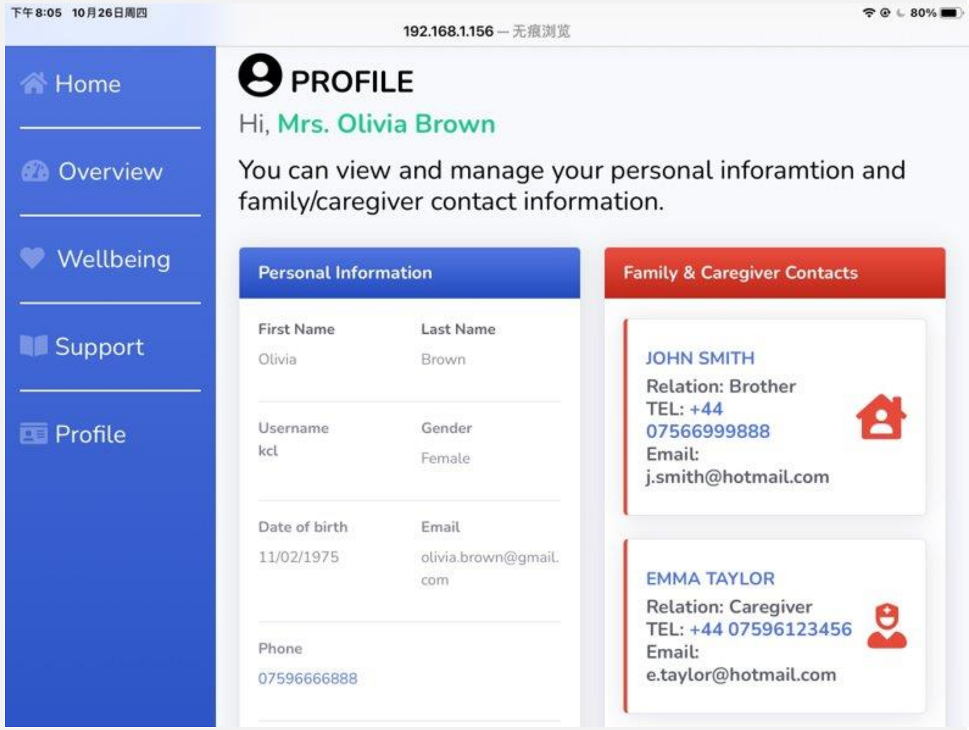
EMMA TAYLOR
Relation: Caregiver
TEL: +44 07596123456
Email: e.taylor@hotmail.com

Personal Details

Family/Caregiver Contacts

UI working well on iPad (tablet)

Portal works well on iPad; nonetheless, smart phone UIs need more front-end debugging work



PROFILE

Hi, Mrs. Olivia Brown

You can view and manage your personal inforamtion and family/caregiver contact information.

Personal Information

First Name: Olivia
Last Name: Brown
Username: kcl
Gender: Female
Date of birth: 11/02/1975
Email: olivia.brown@gmail.com
Phone: 07596666888

Family & Caregiver Contacts

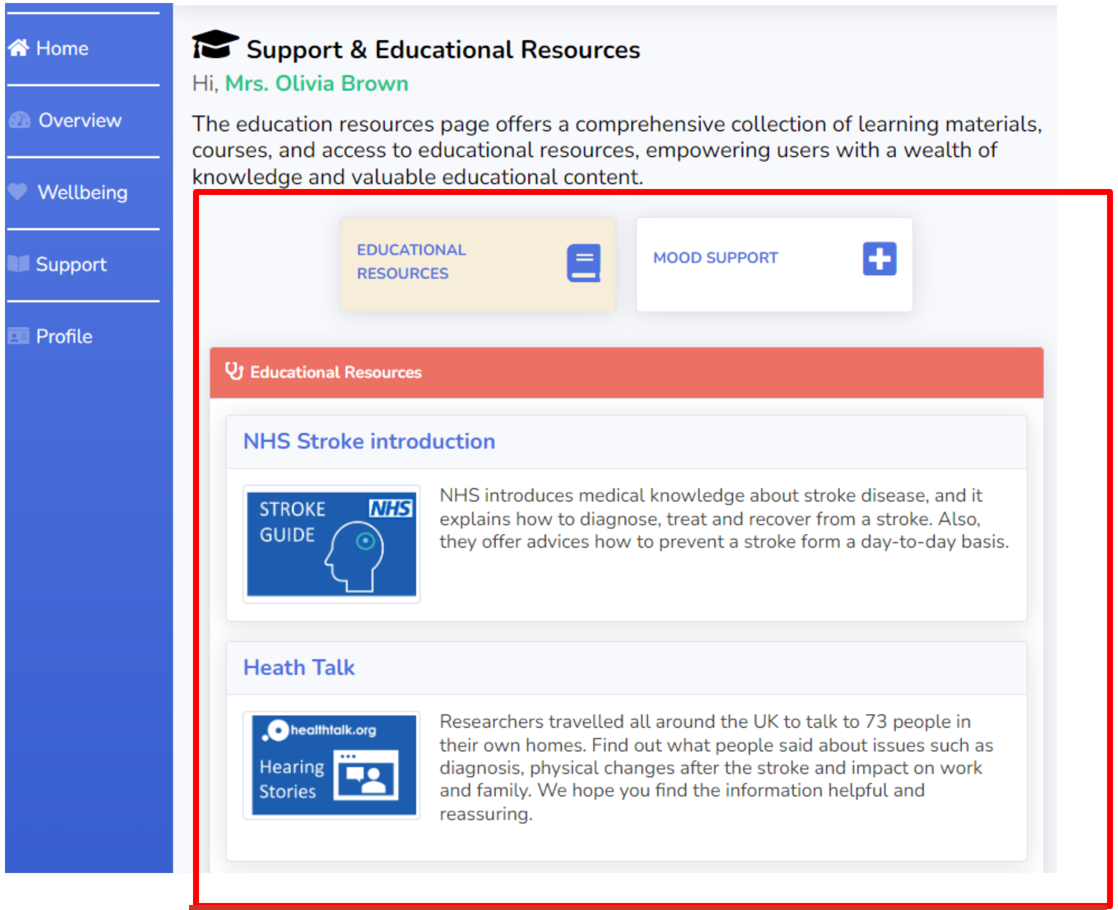
JOHN SMITH
Relation: Brother
TEL: +44 07566999888
Email: j.smith@hotmail.com

EMMA TAYLOR
Relation: Caregiver
TEL: +44 07596123456
Email: e.taylor@hotmail.com

WP3.1 — Functional Patient Portal (3/3)

SNAPSHOTS

SUPPORT - EDUCATIONAL RESOURCES & MOOD SUPPORT



Support & Educational Resources

Hi, Mrs. Olivia Brown

The education resources page offers a comprehensive collection of learning materials, courses, and access to educational resources, empowering users with a wealth of knowledge and valuable educational content.

Educational Resources

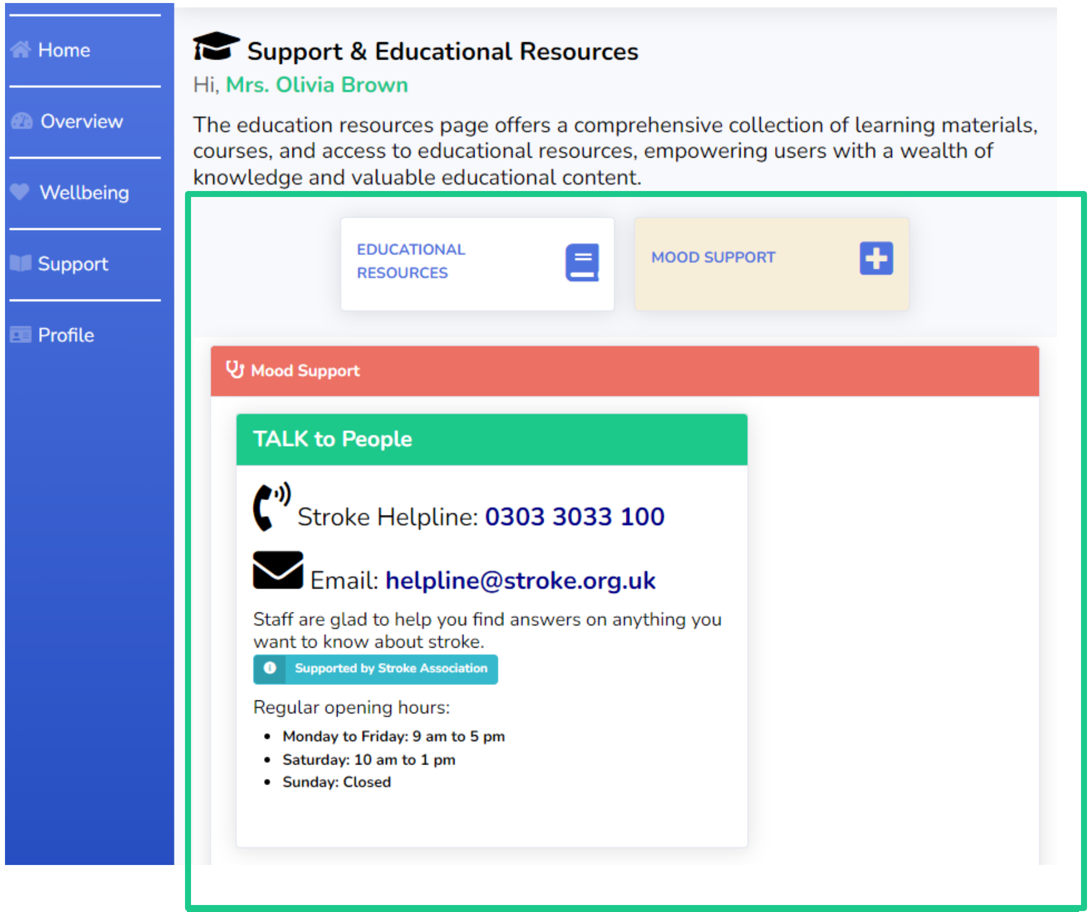
NHS Stroke introduction

NHS introduces medical knowledge about stroke disease, and it explains how to diagnose, treat and recover from a stroke. Also, they offer advices how to prevent a stroke form a day-to-day basis.

Heath Talk

Researchers travelled all around the UK to talk to 73 people in their own homes. Find out what people said about issues such as diagnosis, physical changes after the stroke and impact on work and family. We hope you find the information helpful and reassuring.

Educational Resources



Support & Educational Resources

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Mood Support

TALK to People

☎ Stroke Helpline: 0303 3033 100

✉ Email: helpline@stroke.org.uk

Staff are glad to help you find answers on anything you want to know about stroke.

Supported by Stroke Association

Regular opening hours:

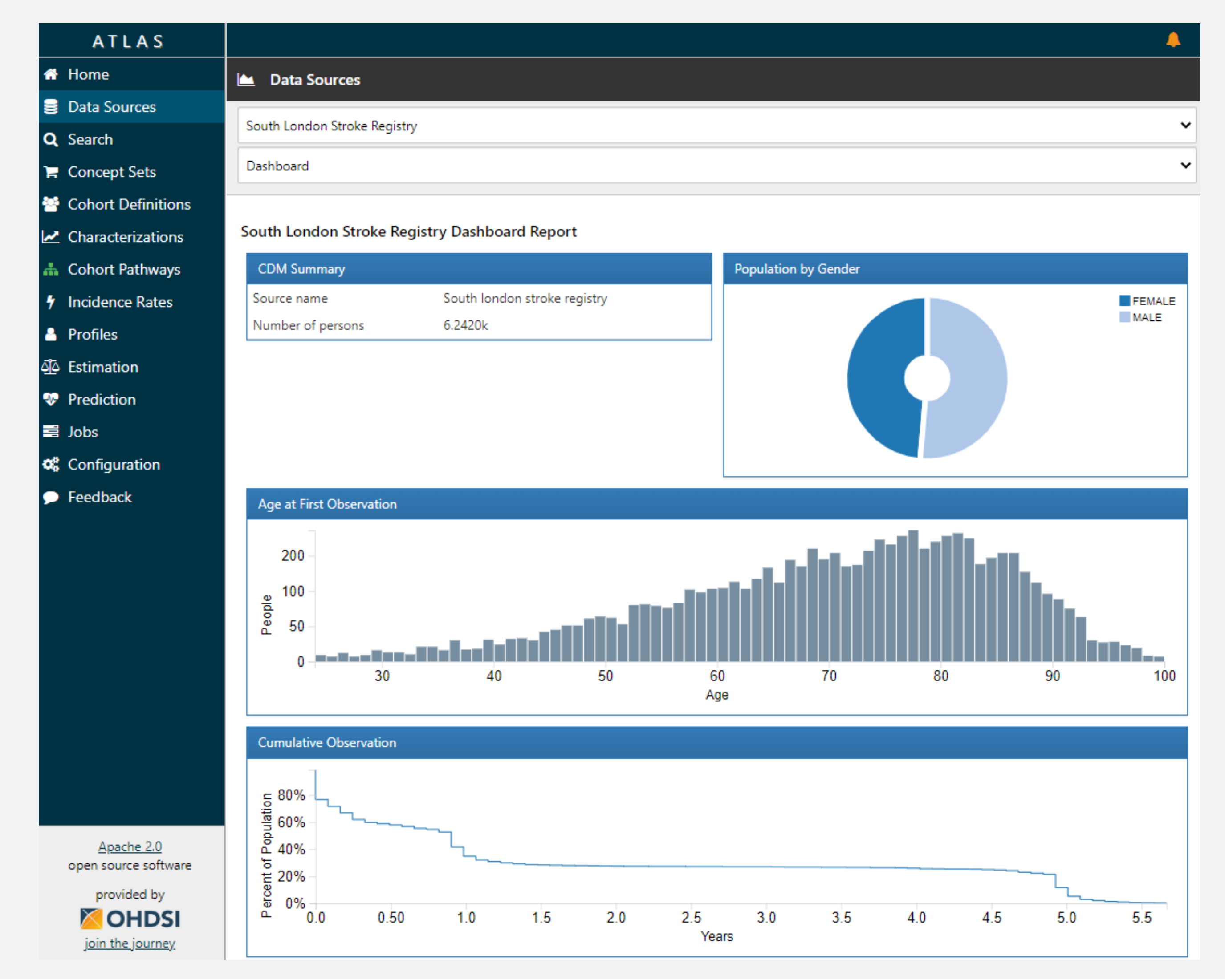
- Monday to Friday: 9 am to 5 pm
- Saturday: 10 am to 1 pm
- Sunday: Closed

Mood support

WP3.2 - Research Portal: Stroke Analytics Dashboard (SAND)

SAND Research Portal

- SAND is web-based research portal using **standardized, patient-level, observational data**;
- SAND helps generate **real-world evidence** from patient level observational data;
- SAND contains **a number of interactive visualisations**, backed up by the registry data, allowing for deep-dives into detailed data.



South London Stroke Registry

Dashboard

South London Stroke Registry Dashboard Report

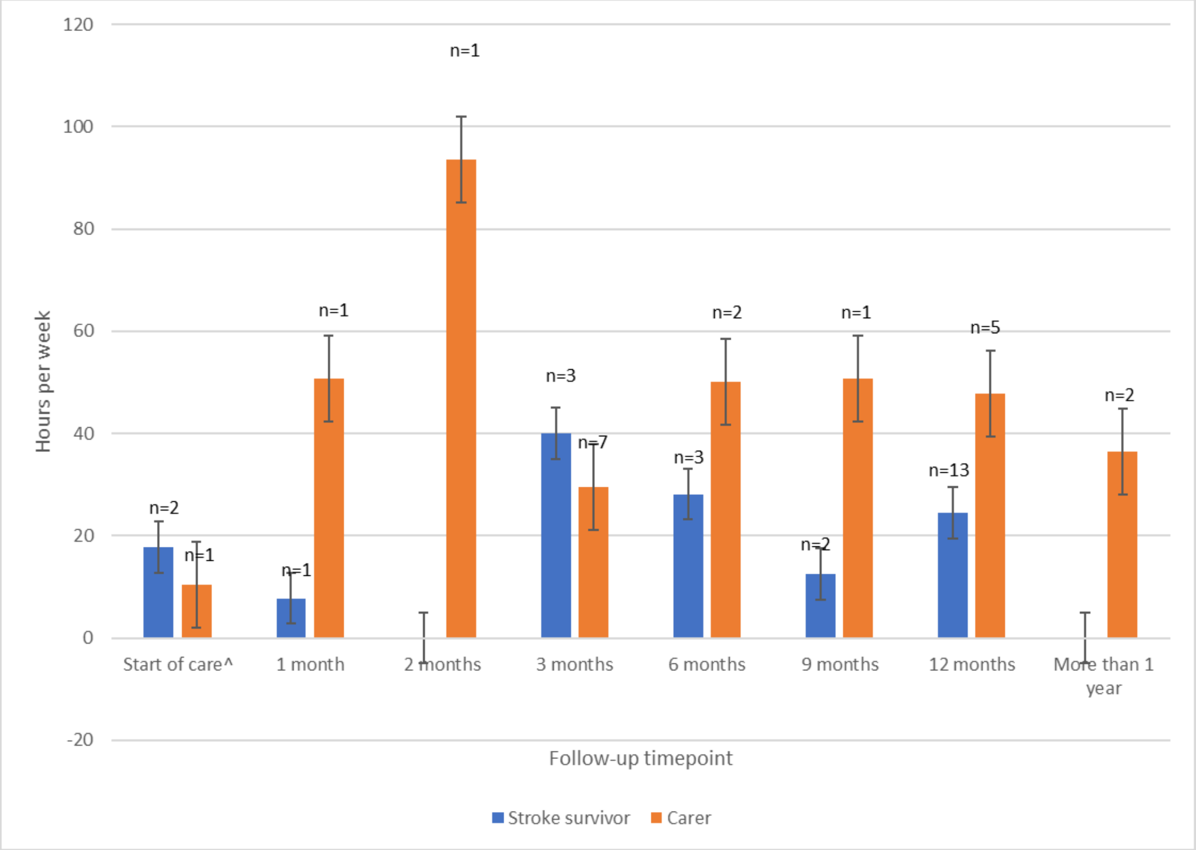
CDM Summary	
Source name	South london stroke registry
Number of persons	6.2420k

Health Economics — Preliminary results

Paper 1: Systematic review of informal care

- 46 papers (representing 44 studies) since 2012 (45% last 5 years), 64% from Europe and 26% from USA & Canada, 54% followed a cohort but 23% used cross sectional design, most used questionnaires (83%) and asked both patient and carers (43%)
- Definition of informal care - It varies widely, most included dressing (70%) followed by bathing (65%), none included emotional or mental support, 33% gave no or unclear definition
- Informal care time - Measured by 12 named and 24 unnamed questionnaires, of which 10 were validated. 43% valued care time, mostly using proxy good method (n=15) followed by opportunity cost (n=4).

Mean time spent caregiving per week, in hours



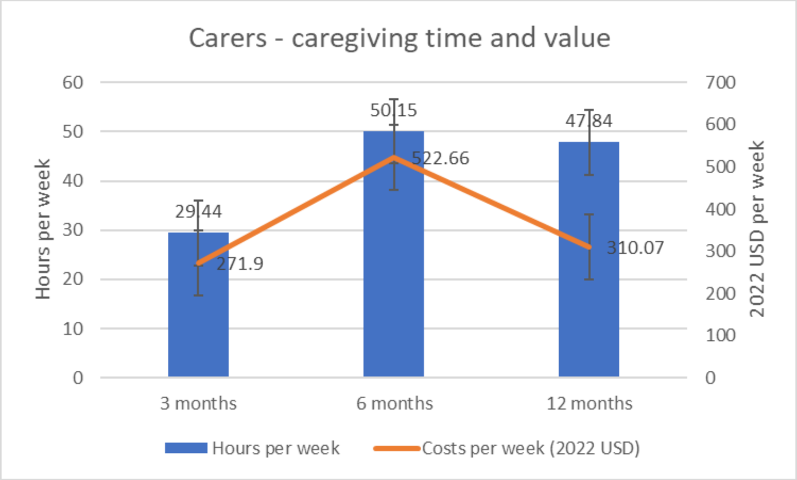
^1 week or less post discharge

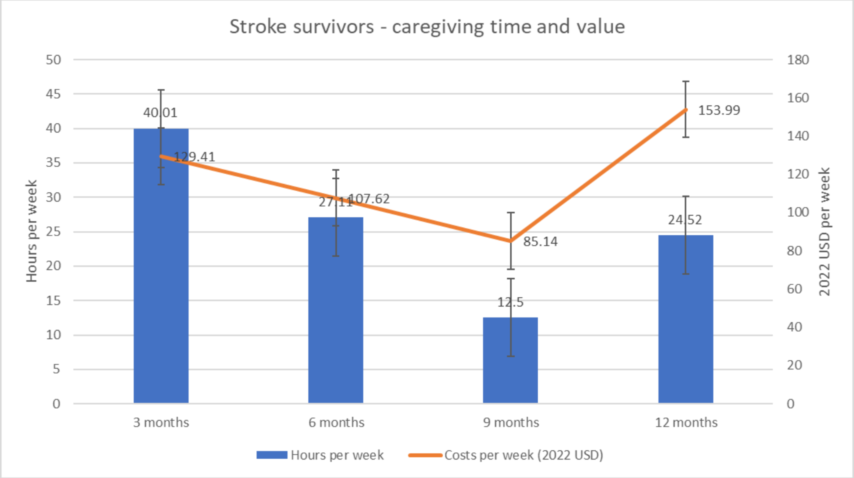
**n is the number of studies reporting data at each timepoint by patient or carer*

Health Economics — Preliminary results

Paper 1: Systematic review of informal care

- After 3 months, carers report an average of 29 hours and stroke survivors 40 hours care a week.





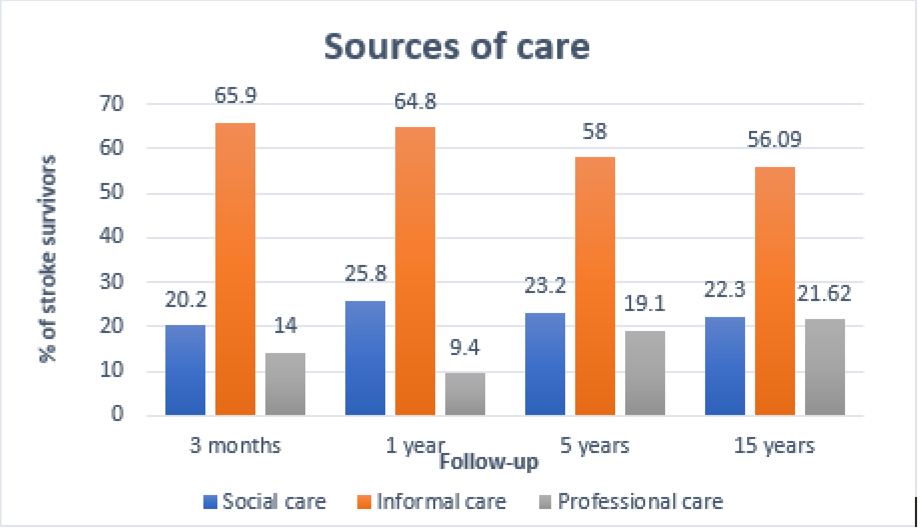
**For studies that reported both time and value of time*

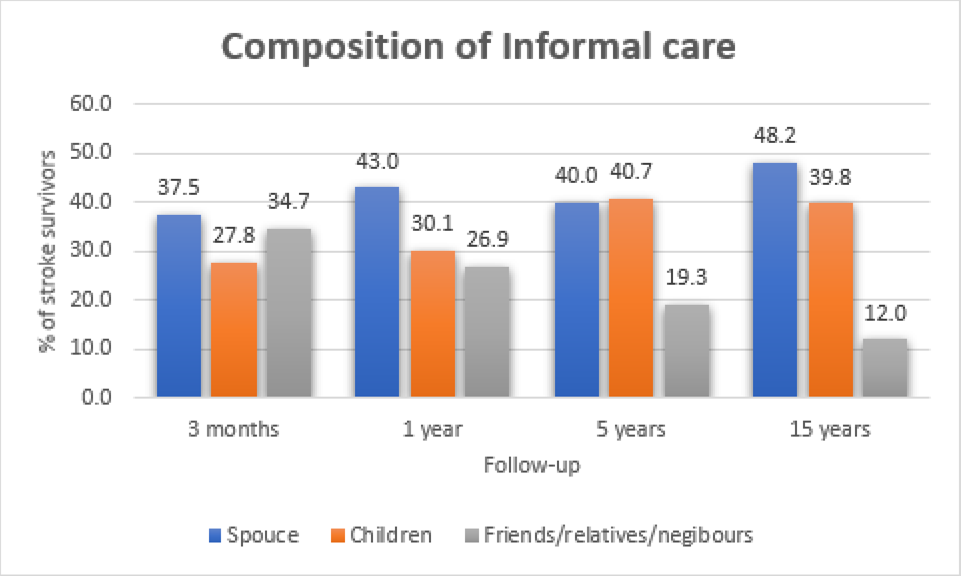
- Quantity of informal care time is related to higher levels of dependency, and number of co-morbidities.

Health Economics — Preliminary results

Paper 2: Care received at home over time: Evidence from SLSR

- 45%, 39% 38% and 40% of stroke survivors receive care at home at 3 months, 1, 5 and 15 years after stroke
- 66%, 65% and 58% of stroke survivors who receive care at home depend on informal care at 3, 12 and 60 months





- Spouse is the main informal carer, followed by children.
- Spouse's contribution as an informal carer increases with the time.

Health Economics — Preliminary results

Paper 2: Care received at home over time: Evidence from SLSR

- People who are older, female, with higher stroke severity and living in private house with others have a higher probability of receiving care at home in all periods

- People of Black African ethnicity have a higher probability of receiving care at home at 3 months. They are more likely to receive care from an external carer and less likely to receive informal care particularly from spouse.

- Females are less likely to receive help from spouse and more likely to receive help from children at 3 months