



IMPROVING THE LIVES OF STROKE SURVIVORS WITH DATA

Stakeholder Engagement Meeting

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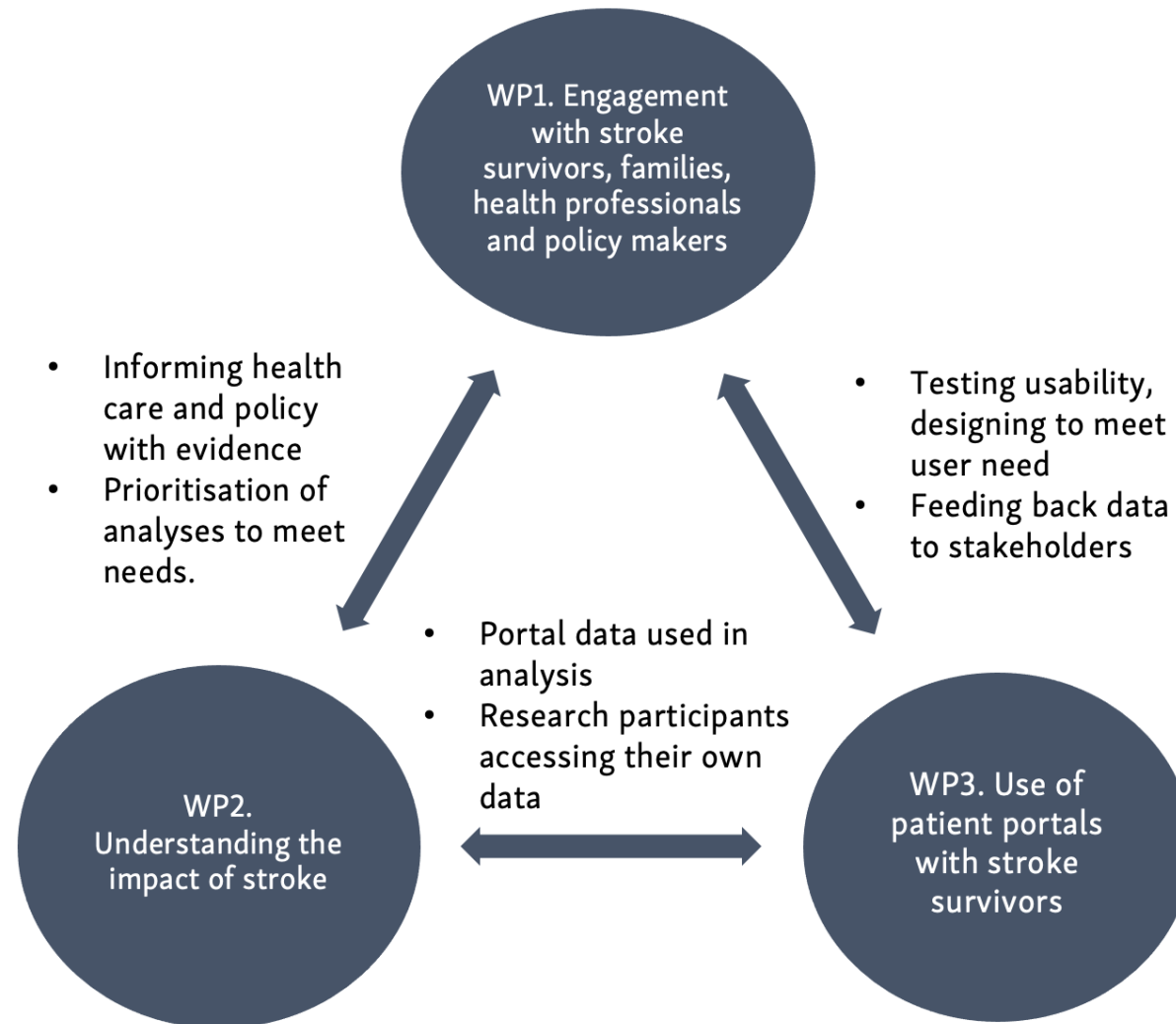
Tianne Haggart

Improving the lives of stroke survivors with data — NIHR Programme Grant

5 year programme, with main aims:

- Maximise potential for stroke data to improve patient care through stakeholder engagement;
- Estimate risk and impact (including economic) of stroke on survivors and society;
- Produce clinical, epidemiological and economic models to make informed decisions;
- Investigate how patient portals can improve stroke survivors' decision making/outcomes.

Improving the lives of stroke survivors with data — NIHR Programme Grant



WP1 — Engaging with stroke survivors, families, health professionals and policy makers



This social science Work Package comprises three interlinked research elements. It also houses involvement and engagement work.

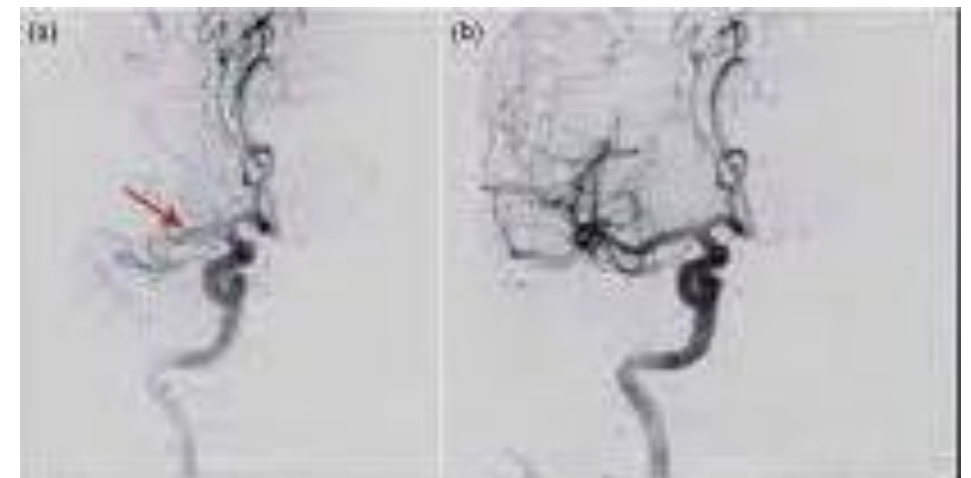
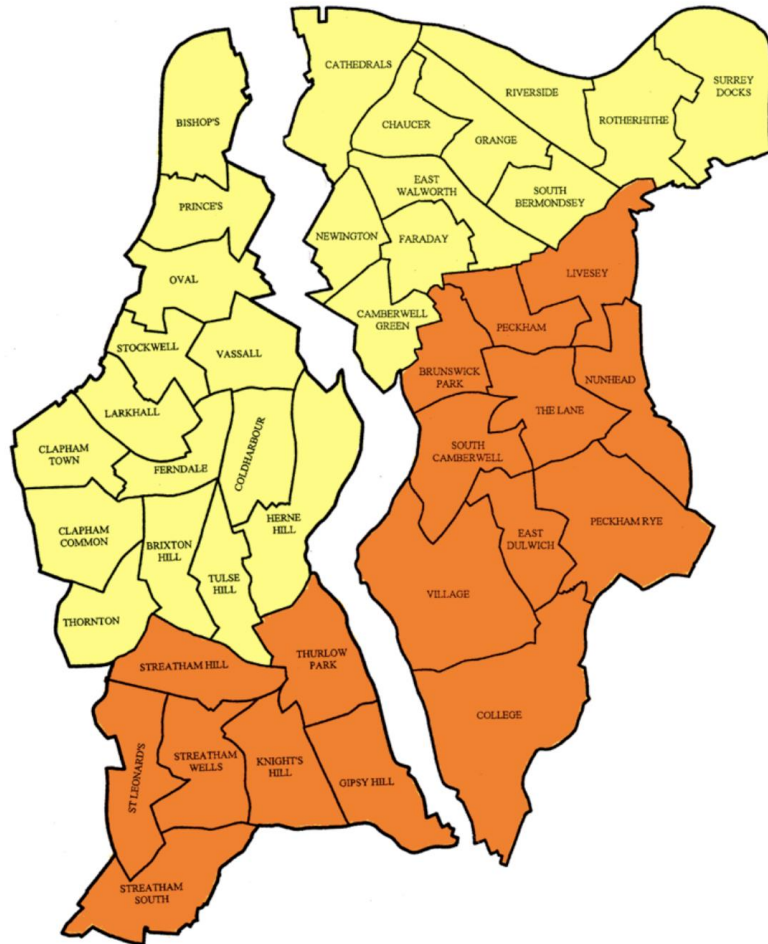
Research Element 1: Evaluation of the impact of the Stakeholder Engagement Group

Research Element 2 : Study on the informal costs of care (to input into the SLSR)

Research Element 3: Study on the information needs of stroke survivors, carers, and other key stakeholders in stroke care and stroke policy.

Involvement and Engagement Work: Patient and Public Involvement; Stakeholder Engagement Group; Policy Labs

WP2 — Understanding the impact of stroke in the 2020s (ICD 11)



WP2 — Understanding the impact of stroke in the 2020s (ICD 11)

Work package comprises 3 strands of work:

- **Establish a new cohort of ICD-11 patients**

- Understand the incidence and outcomes of the new definition

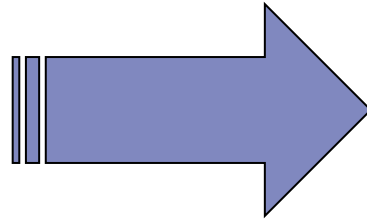
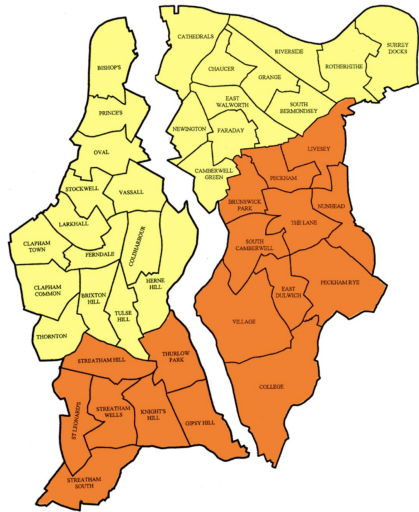
- **Analyse established database of >7500 enrolled patients**

- Understand long term changes in patient health

- **Develop statistical tools to support practice and policy**

- Predict individual recovery and project changes in patient population

WP3 — Use of portals with stroke survivors and policy makers



Health economics research across the programme

Health economics team: Professor Julia Fox-Rushby, Carina Bektur



WP1: Engagement with stakeholders

- systematically review methods of measuring and costing informal care;
- evaluate and develop survey measures to assess informal care over time.

WP2: Understanding the impact of stroke using data

- use the SLSR to describe use of health, social and informal care by stroke patients over time from 1 to 15+ years after stroke and the relationship to stroke recovery;
- project the costs of stroke under ICD-11.

WP3: Use of patient portals

- analyse new informal care survey results;
- evaluate the cost-effectiveness of the patient portal.

Stakeholder Engagement Group

Purpose:

- To provide oversight of the programme from all stakeholders' perspectives
- To engage all key stakeholders in the development of new ways of improving the lives of stroke survivors with data
- To contribute to shaping the programme's research so it meets the needs of stakeholders and is academically, clinically but also socially robust.

In practice:

- Biannual meetings (although exact structure is open for discussion)
- Invitations to be involved in other aspects of the research, for example, Policy Labs

Stakeholder Engagement Group - Evaluation

In line with calls for critical evaluations of PPI and engagement, the evaluation moves away from measure to quantify impact (i.e counting the number of people involved) and will:

- document practices and outcomes to demonstrate where and how the SEG has been involved in and actively shaped the research practices and outputs. evidence where the SEG were less involved in decisions.
- Provide guidance for future SEGs in other research settings on effective engagement

On-going feedback and interim evaluation report (Year 3) will enable SEG and project team to work to improve collaboration over the course of the project.

Final evaluation report (Year 5)

WP1 — Engaging with stroke survivors, families, health professionals and policy makers

- HRA and site approvals received for all WP1 work.
- PPI participants recruited and initial, informal meeting held.
- Stakeholder Engagement Group participants recruited, and first meeting arranged.
- Literature scoping work underway (including a systematic literature review with health economics team) and interview schedule drafted for informal cost of care work (WP1.2)

Next six months:

- Complete 60 patient interviews and data analysis (WP1.2)
- Start data collection on informational needs of different stakeholders (WP1.3)
- Design and complete first Policy Lab

WP2 — Understanding the impact of stroke in the 2020s (ICD 11)

- Protocols updated for ICD-11 and new areas of focus
- Ethical approval received after extensive application
- New fieldwork began April 22
- Initial priority analyses planned for established database

Next 6 months

- Confirm final scales to be added to data collection
- Complete covid data entry back long to include most up to date data for established cohort
- Complete first batch of priority analyses – updates to incidence, real world effects of treatment, stroke frailty index, cohort description

WP3 — Use of portals with stroke survivors and policy makers

- Newly recruited research associate Dr Zhiqiang Huo (health informaticist) starting soon
- Background work completed translating stroke register to 'OMOP' format
- Next 6 months:
 - Initial designs for patient portal (including work with this group)
 - Working on baseline version of portal

Fatigue and communication in SLSR - new data collection

We are expanding SLSR data collection for the new programme

We aim to ensure our data meets the needs of all stakeholders

Fatigue and communication were identified as priority areas by the James Lind Alliance

We would appreciate your thoughts on some potential scales



Fatigue and communication in SLSR – current items

Fatigue – SF12 energy item

How much time during the last month:	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
A. Have you felt calm and peaceful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B. Did you have a lot of energy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C. Have you felt downhearted and low?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D. Has your health limited your social activities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Communication – Speech item

24. Do you currently have slurred speech or problems talking to somebody because your mouth was unable to articulate words or sentences correctly due to your stroke?

- Yes
- No
- Unknown

Fatigue and communication in SLSR

FATIGUE SEVERITY SCALE

During the past week, I have found that:	Strongly Disagree			Neither Agree Nor Disagree			Strongly Agree
1. My motivation is lower when I am fatigued.	1	2	3	4	5	6	7
2. Exercise brings on my fatigue.	1	2	3	4	5	6	7
3. I am easily fatigued.	1	2	3	4	5	6	7
4. Fatigue interferes with my physical functioning.	1	2	3	4	5	6	7
5. Fatigue causes frequent problems for me.	1	2	3	4	5	6	7
6. My fatigue prevents sustained physical functioning.	1	2	3	4	5	6	7
7. Fatigue interferes with carrying out certain duties and responsibilities.	1	2	3	4	5	6	7
8. Fatigue is among my three most disabling symptoms.	1	2	3	4	5	6	7
8. Fatigue interferes with my work, family, or social life.	1	2	3	4	5	6	7

Because of my fatigue during the past 4 weeks

	Never	Rarely	Sometimes	Often	Almost Always
1. I have been less alert.	0	1	2	3	4
2. I have had difficulty paying attention for long periods of time.	0	1	2	3	4
3. I have been unable to think clearly.	0	1	2	3	4
4. I have been clumsy and uncoordinated.	0	1	2	3	4
5. I have been forgetful.	0	1	2	3	4
6. I have had to pace myself in my physical activities.	0	1	2	3	4
7. I have been less motivated to do anything that requires physical effort.	0	1	2	3	4
8. I have been less motivated to participate in social activities.	0	1	2	3	4
9. I have been limited in my ability to do things away from home.	0	1	2	3	4
10. I have trouble maintaining physical effort for long periods.	0	1	2	3	4
11. I have had difficulty making decisions.	0	1	2	3	4
12. I have been less motivated to do anything that requires thinking	0	1	2	3	4
13. My muscles have felt weak	0	1	2	3	4
14. I have been physically uncomfortable.	0	1	2	3	4
15. I have had trouble finishing tasks that require thinking.	0	1	2	3	4
16. I have had difficulty organizing my thoughts when doing things at home or at work.	0	1	2	3	4
17. I have been less able to complete tasks that require physical effort.	0	1	2	3	4

Krupp et al.[4]. Copyright © 1989 American Medical Association. All rights reserved.

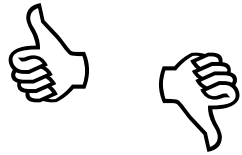
Other options – fatigability scale, further energy items

Fatigue and communication in SLSR

COAST scale

Item 1. In the past week or so how well could you

show that you mean **YES** or **NO**?



Couldn't
do it at
all

With a
lot of
difficulty

With
some
difficulty

Quite
well

Very
well

Detailed scale – 20 items

Uses visual aids, detailed script, non-verbal cues –
pointing etc

Not feasible in current interview format

Other options?

Fatigue and communication in SLSR

How relevant are these for questions to stroke patients' experience?

How useful are these question for stroke care and policy?

What are the key points about fatigue and cognition in stroke?

Any other suggestions?

Patient Portal & Stroke Analytics Dashboard

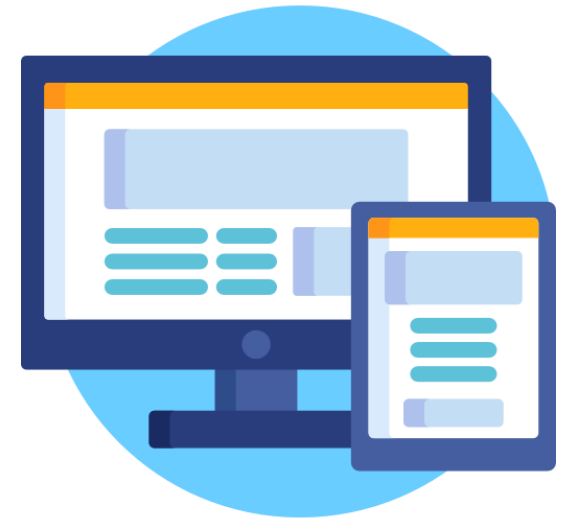
Timothy Neate* (and Vasa Curcin)

*Lecturer, Department of Informatics, King's College London

Overview

We are building **two technologies** which enable better engagement with the South London Stroke Register (SLSR)

- A personalized **patient portal** for stroke survivors
- A public **stroke analytics dashboard** for policy makers, research community, others



Patient Portal

Will support **stroke survivors** to manage their health

Provide integration, e.g. to **fitness sensors**

Decision support to help manage health concerns

Support a **forum** for discussion about health



Patient Portal: Challenges

Currently patient portals **do not work** for some – too hard to use, no motivation, etc.

We want to show you the portal **as it's built**, so that we can get your feedback



Stroke Analytics Dashboard

Will support **policy makers**, the **research community** and **public** to access stroke data

Will include a range of **visualizations** and ways to present data

With a more **detailed view** for researchers



Where you come in

We want your **feedback** on the portal and dashboard

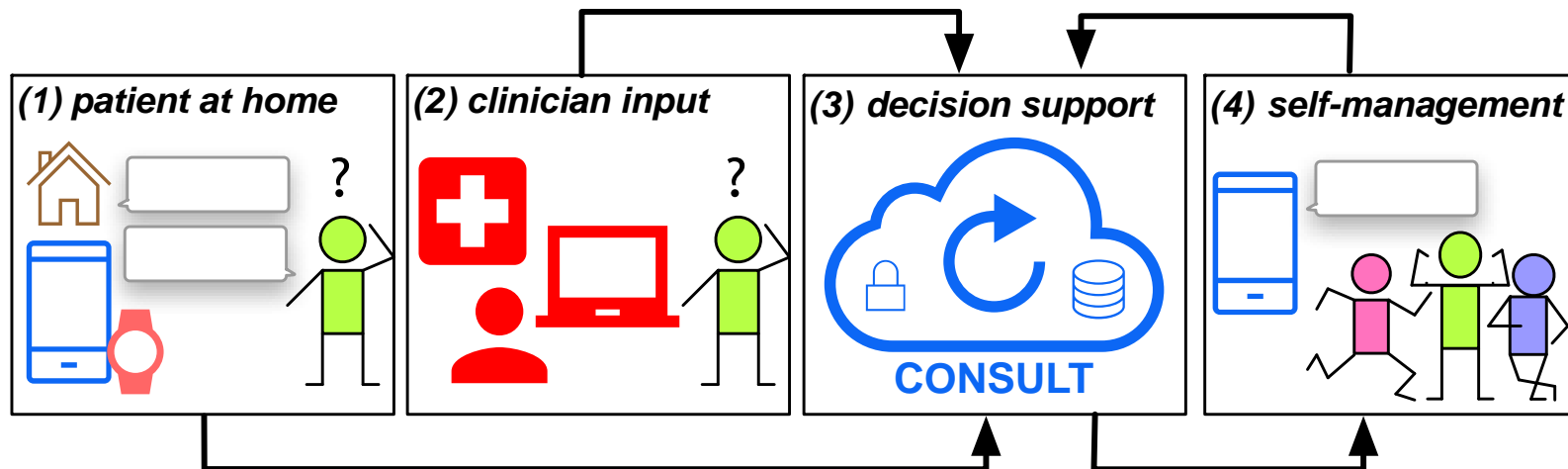
We will ask you for **feedback** as they progress



Our Starting Point: CONSULT

This project's **starting** point is **CONSULT** (Vasa Curcin)

CONSULT is a **previous** project aimed at using **wellness** sensors to support patients' **healthcare**

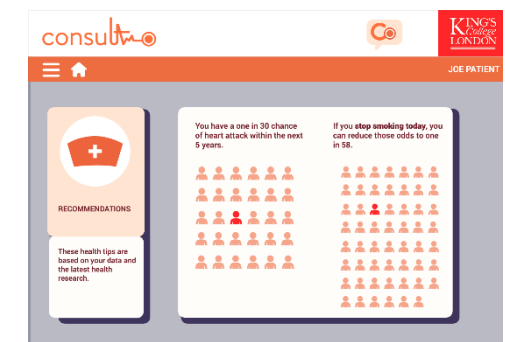
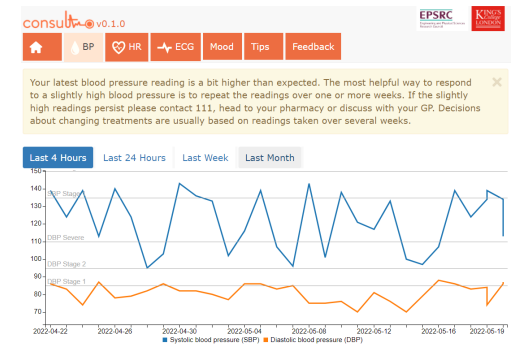


Our Starting Point: CONSULT

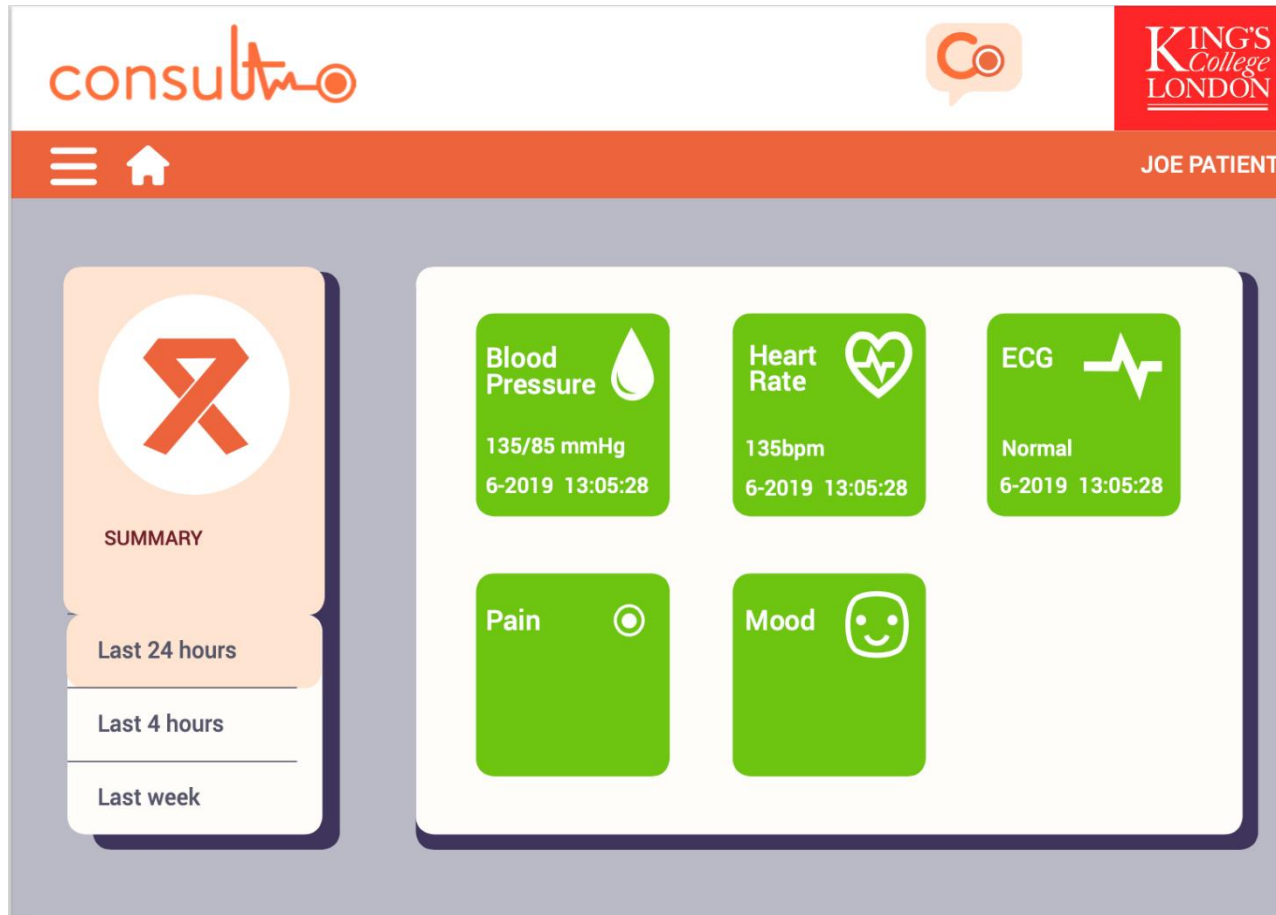
We will **build upon** some aspects of CONSULT

Aim to make the tool **accessible** for all stakeholders to **use stroke data**

Some aspects of CONSULT will be explained **explain** what we mean by '**portal**'



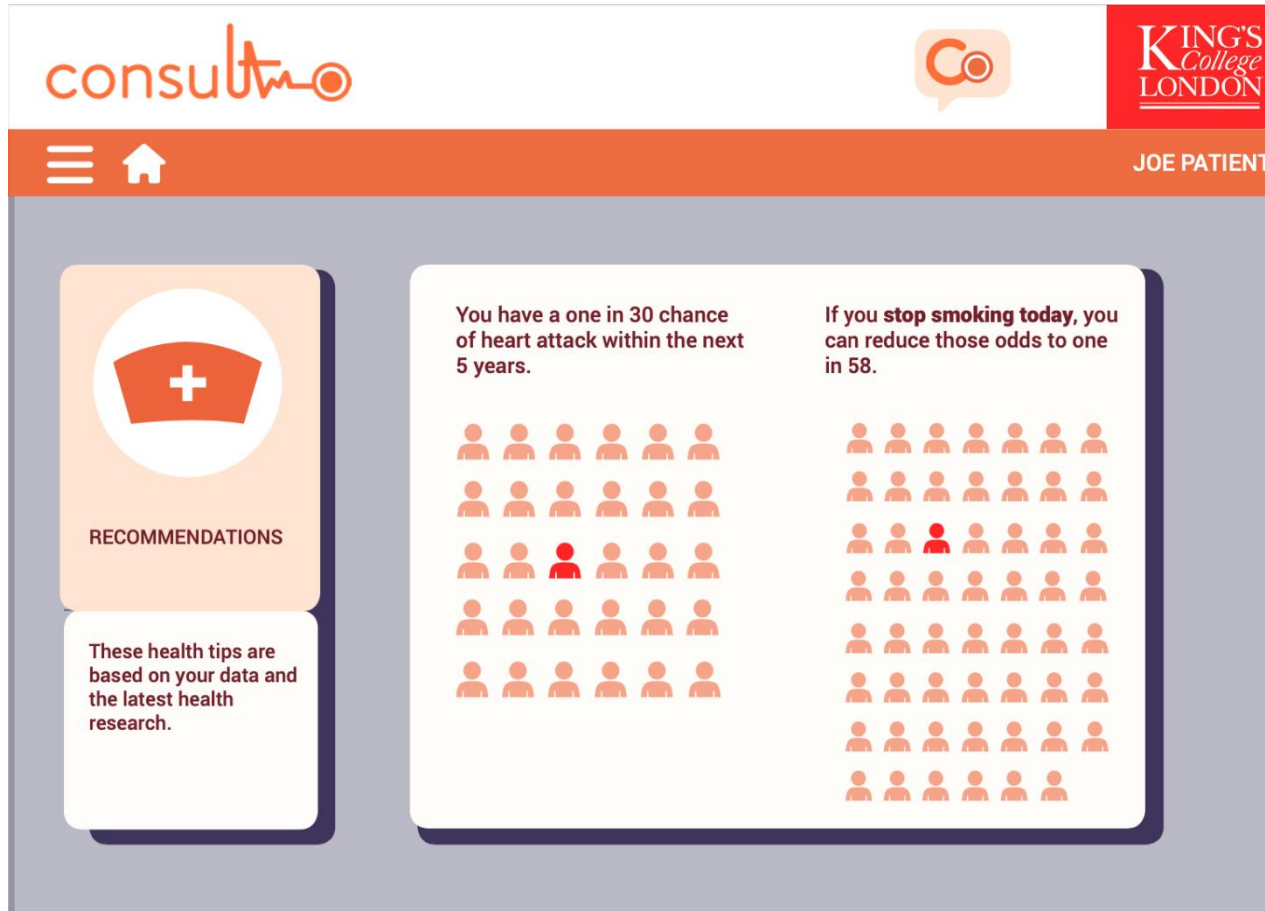
CONSULT



Consult contains information about **healthcare data**

Some **self-reported**, some from **sensors**

CONSULT



Visualizations based on your health data

Recommendations and key **insights**

CONSULT



More **sophisticated** breakdowns for those who want it

Text summaries of data

Some questions for you!

We want to get some initial ideas from you

No wrong answers!

Patient Portal: Your Initial Thoughts

Imagine a portal where **stroke survivors** could get information on **their health** at any point

- What would be its **key functions**?
- How would it present **your information**?
- What **device(s)** would this be on?

Patient Portal: Your Initial Thoughts

Imagine a portal where stroke survivors could get information on their health at any point

- And the information of **others**? For example, to compare yourself
- **Anything else** you think is important?

Stroke Dashboard

Imagine you wanted to **understand** more about **stroke** data (or an individual patient's stroke data)

- How would this data be presented?
- What types of information would you prioritize?
- What are the key **statistics or inferences** you'd want to see/make?
- **Anything else** you think is important?