

# Managing fatigue after stroke: co-design of a self-management programme

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**COMbAT Fatigue**

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**NIHR**

National Institute for  
Health and Care Research

**Stroke**  
Association



**UNIVERSITY OF  
BIRMINGHAM**

# Post-stroke fatigue



Half of stroke survivors experience fatigue



Many report fatigue to be their **worst symptom**



Improving management is a **high-priority** area for research

# Post-stroke fatigue

Can affect **all stroke survivors**

Can impact **all aspects of life**



Rehabilitation



Stroke prevention



Mental health



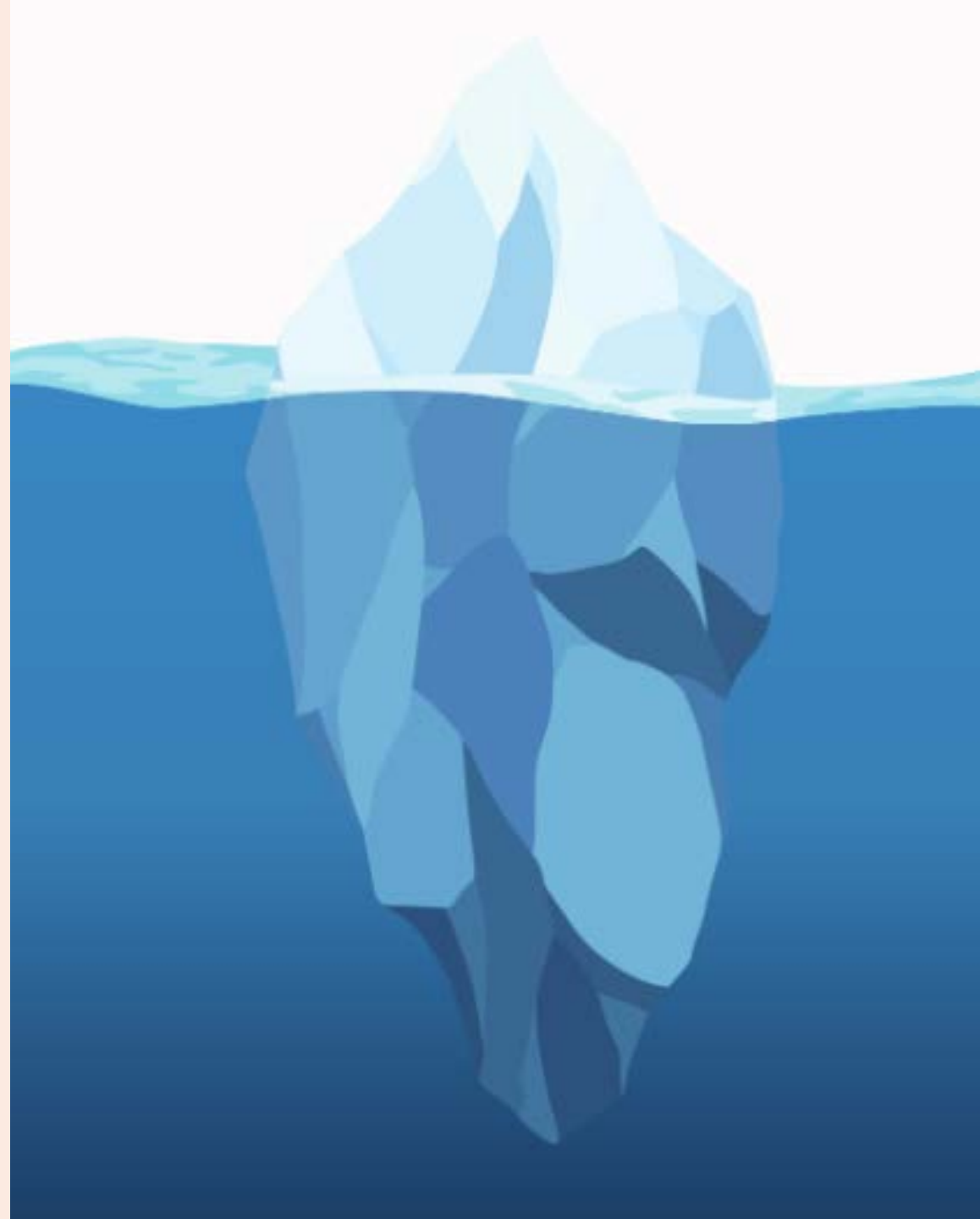
Daily lives



Work



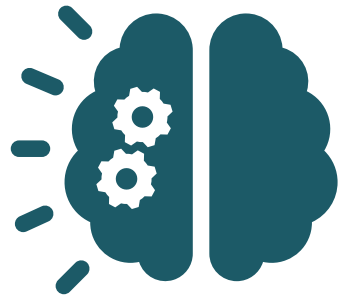
Family & friends



# Post-stroke fatigue



Why do people get fatigue after stroke



## Primary:

Inflammation, disrupted brain networks



## Secondary:

Depression/ mood, sleep, diet, stroke-related impairment

# Post-stroke fatigue

**Lack of guidance:** Clinicians rely on their own knowledge and experience

**Variability:** Healthcare setting, professional background and experience

**Lack of scientific evidence**



# Aims

*5-year programme grant*

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1

**Co-produce** a self-  
management programme  
for fatigue and  
implementation pathway

2

Evaluate the  
**effectiveness** and  
**cost-effectiveness** of  
the programme

# Adapt



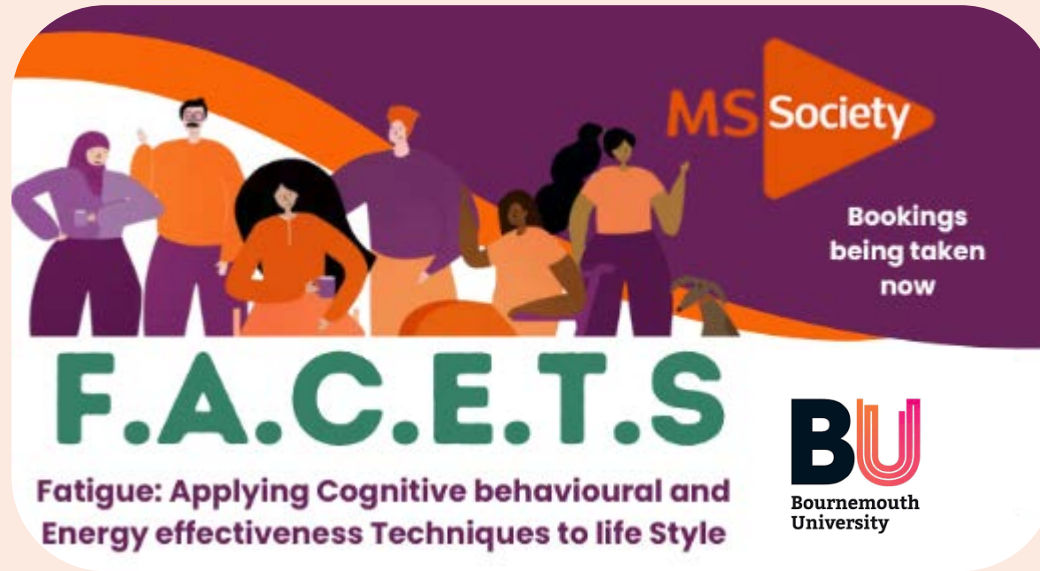
Evidence-based,  
effective for MS

Successfully  
implemented for MS

Used unofficially in  
stroke and neuro rehab

Core components align  
with stroke literature

# Adapt



Evidence-based,  
effective for MS

Successfully  
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Used unofficially in  
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Core components align  
with stroke literature



Group based: 6 weeks



Normalise  
fatigue



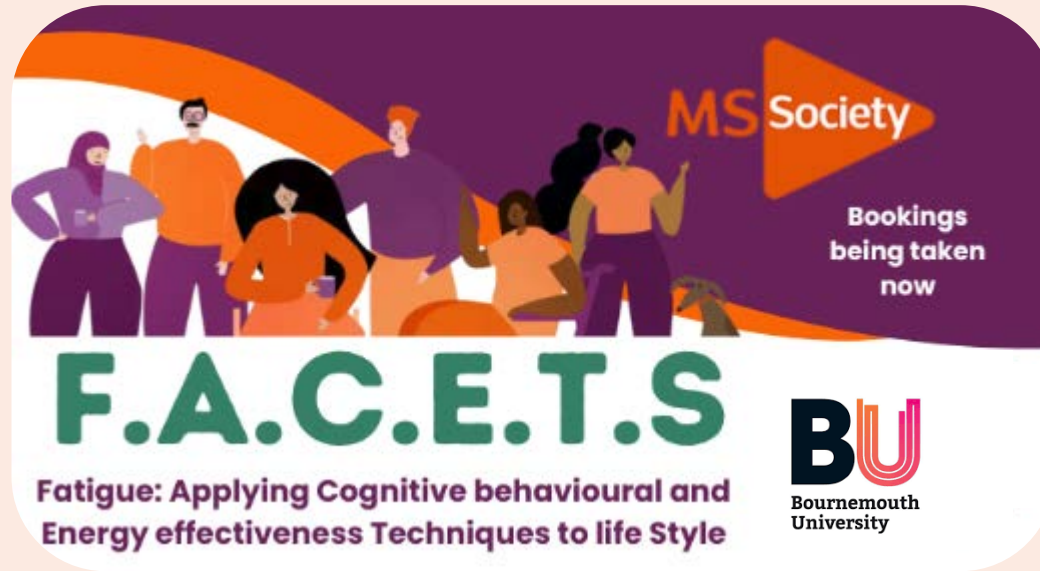
Use energy more  
effectively



Address negative  
thoughts



# Adapt



Evidence-based,  
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a

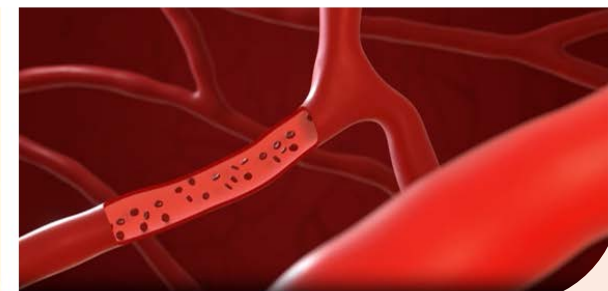
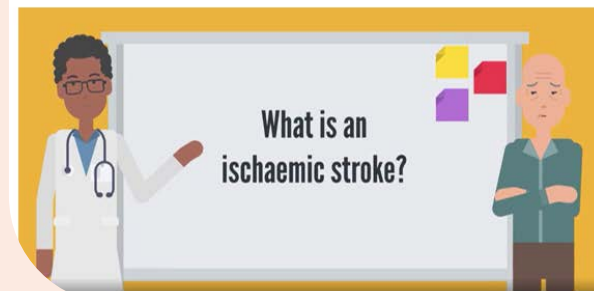
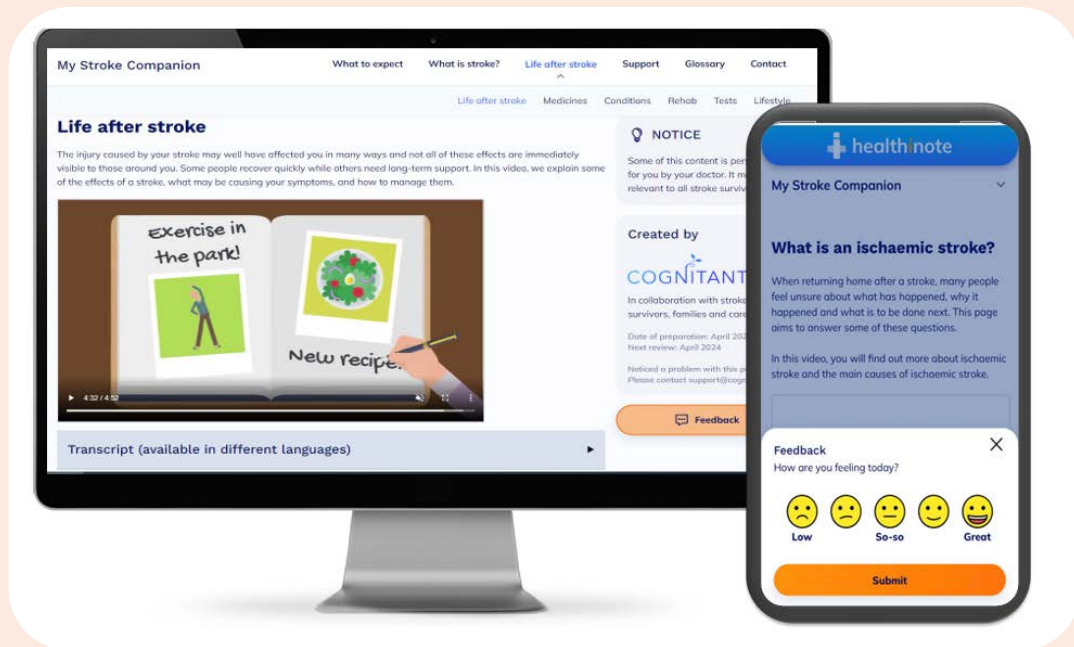
Adapt **content**:  
for the stroke population

b

Adapt **delivery**:  
web-based, self-administered  
with HCP support

# Web-based delivery

COGNITANT



# Web-based delivery



Mobility/ transport



Work/ caring commitments



Dislike groups



NHS capacity



Aphasia: pictures/infographics,  
short messages, re-watch



Impaired hearing: subtitles



Visual problems: audio, large print



Non-English language: translation



## COMBAT Fatigue

WP-1



**Understand “context”,**  
Behaviour analysis,  
Logic modelling.

WP-2



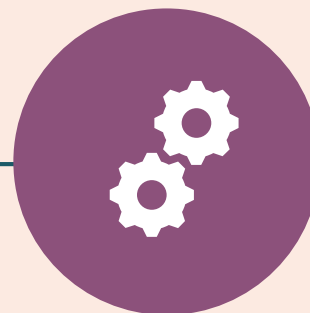
**Co-production:**  
Intervention  
development

WP-3



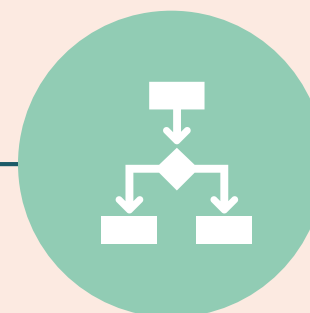
**Usability:**  
Think aloud,  
Usability  
questionnaires,  
Interviews.

WP-4



**Feasibility study:** Single  
arm,  
multi-site.

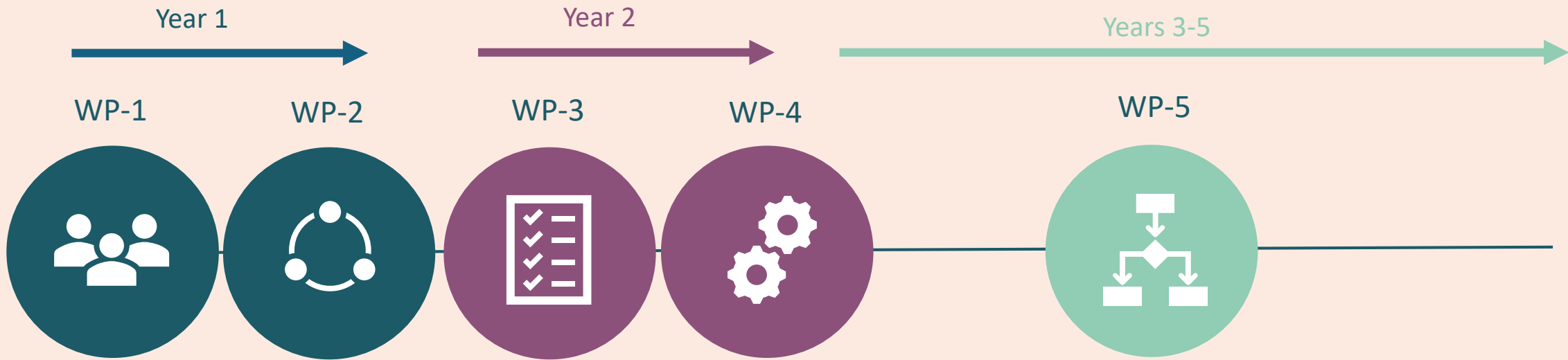
WP-5



**RCT:**  
Health economic  
evaluation,  
Process evaluation.



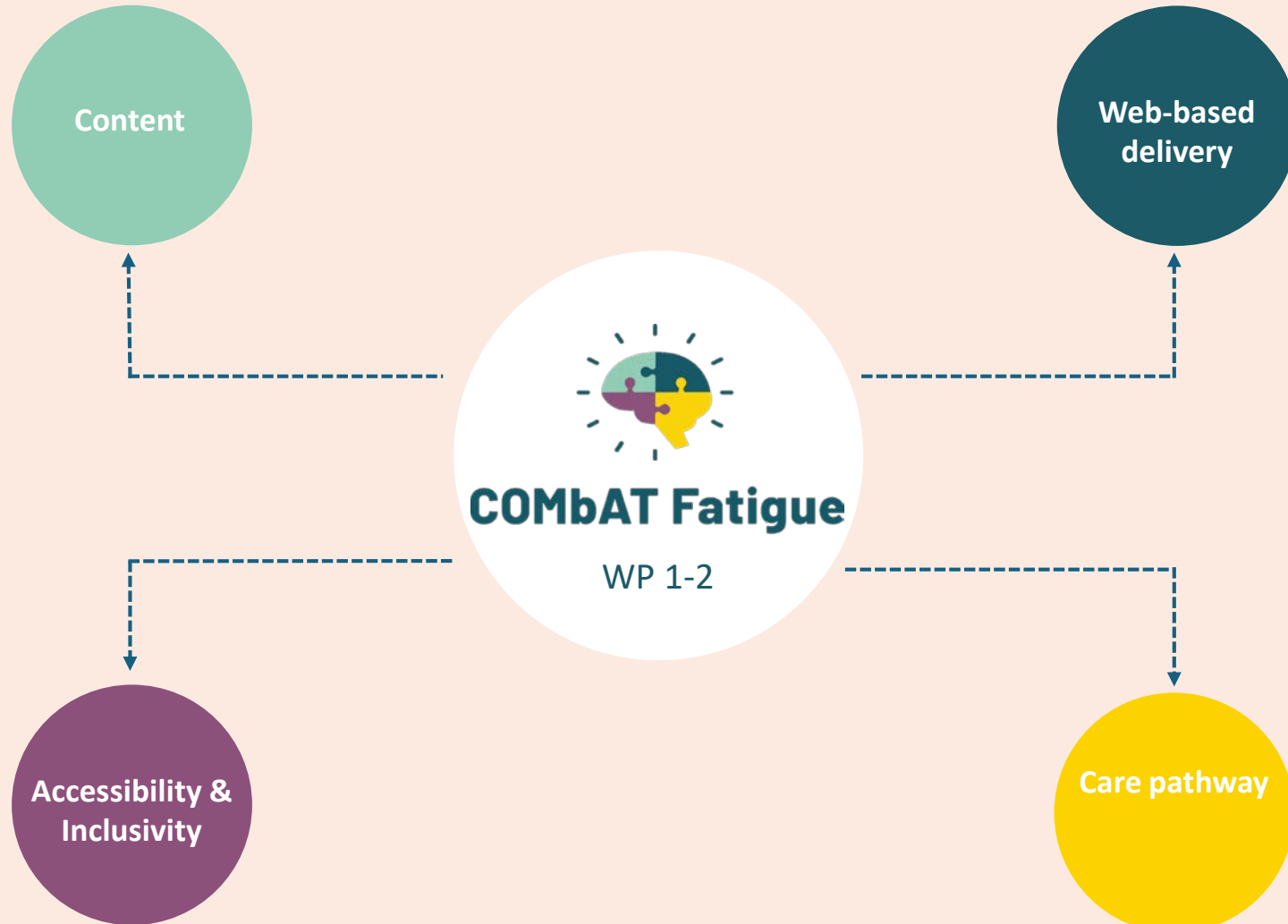
# COMbAT Fatigue



# Co-production



- ADAPT guidance
- MRC guidance for developing/evaluating complex interventions,
- Person-based approach,
- NIHR co-production guidance



# Co-production



Aphasia



Conversation Group



Vision



Digital exclusion



Ethnicity



# Co-production



5 x Focus groups (**n=36**)  
Interviews (**n=6**)



Delivered original  
FACETS (**n=9**)



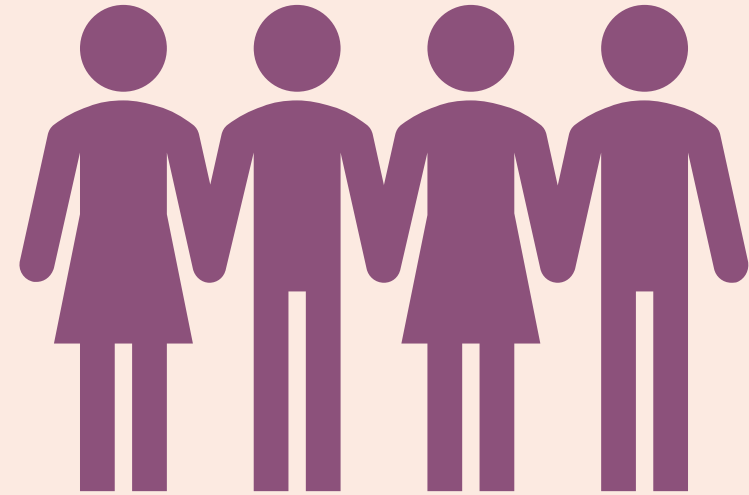
6 x Workshops  
(**n=9**)



Ad hoc consultation



Understanding and  
normalising fatigue



## Knowledge gaps

- **General information** on fatigue e.g., prevalence, duration/recovery time
- **How to help family/friends** understand fatigue so they can better support stroke survivor.

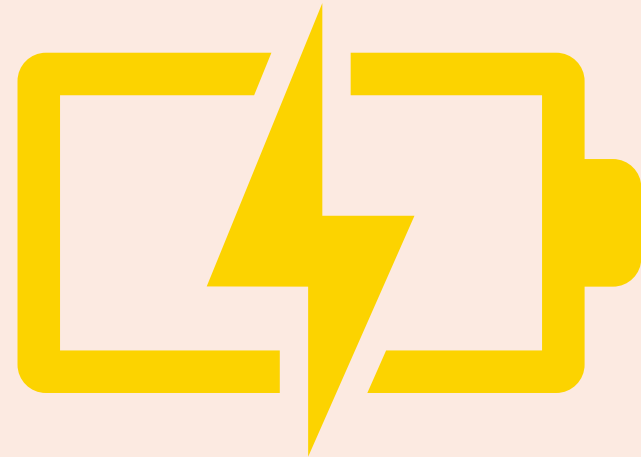
## Barriers to understanding and accepting fatigue

- Lack of **acceptance**
- **Mental health** - feelings of loss and devastation
- **Recovery process:** competing needs/issues
- Difficult to **differentiate fatigue** from other stroke issues

## Motivation to engage in the course – potential drivers

- Understanding **potential benefits** of programme
- Receiving information about course from a **credible source** e.g., HCP such as speech therapist, physiotherapist or occupational therapist
- **Involving supportive family and friends**

Using energy more  
effectively



## Motivation to engage with strategies – potential drivers

- **Understanding the value and benefit** of tips
- Understanding what could happen if you **don't use strategies**
- **Not wanting to miss out** of activities with friends and family e.g., would want to learn how to prioritise tasks
- **Setting smaller goals** to enable person to do some of what they could do before the stroke

## Motivation to engage with strategies – potential barriers

- **Lack of motivation** - mental health problems and physical health restrictions
- **Physical** challenges
- **Fatigue** itself making it difficult
- Other **competing priorities** – other stroke symptoms/rehab, lack of time, work and caring responsibilities
- **Lack of confidence** in strategies due to previous ill success
- Issues around **acceptance and utilisation/uptake** of strategies – don't want to accept/appear 'unwell'

Address negative  
thoughts



## Adoption of helpful thinking styles – potential enablers

- **Better information provision** → better preparation and knowledge around what to expect. Avoid disappointment and frustration.
- **Understanding differences between mental and physical fatigue** – and how they can affect mood.
- **Better understanding and acceptance** of ‘new you’ following stroke (‘rebirth’)

## Adoption of helpful thinking styles – potential barriers

- People thinking they **will ‘get better quickly’**, then when this does not happen it is difficult to change mindset.
- Perceived **pressure to appear ‘well’** to family and friends = pretending that they are ‘fine’. Makes it difficult then to identify thinking styles as ‘unhelpful’ and therefore adopt more ‘helpful’ ones.
- **Feeling like a ‘victim’** of stroke.

## Potential enablers to aid the identification of unhelpful thoughts related to fatigue and creating alternative more helpful ones

- **More information on how to identify ‘unhelpful’ thinking styles** and how to manage these
- **Positive support from friends and family** – to help in the identification of unhelpful thinking styles
- **Input from healthcare providers** on what to expect and how to identify unhelpful thinking styles

# Care pathway

- 6-month Stroke review
- Community stroke/ neuro rehab
- GP practice: long-term condition review
- Stroke Association: commissioned services



# Team



Co-leads



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Caroline  
McKay



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Sarah  
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Jowett



PCPIE leads



Dr Steven  
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Dr Phil  
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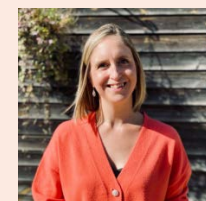
Katy  
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Daisy Allington



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