Designing a new measure for cognition after stroke

Easy access report

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What is this book?

This is a **short final report** on a set of studies that designed a new measure for stroke.

It is written for **people with stroke** who may have difficulty **reading or understanding**. It tells you most of the points but in less detail.

Why have I received it?

You, or your family, **kindly took part** in one of the studies. Or you **helped us to plan and run it**.

The studies included people who had their stroke several years ago. We express our sympathies to anyone since bereaved.

If you have **any questions** about this book, please **contact me**, Emma Patchick. My **contact details** are on the **front cover**.
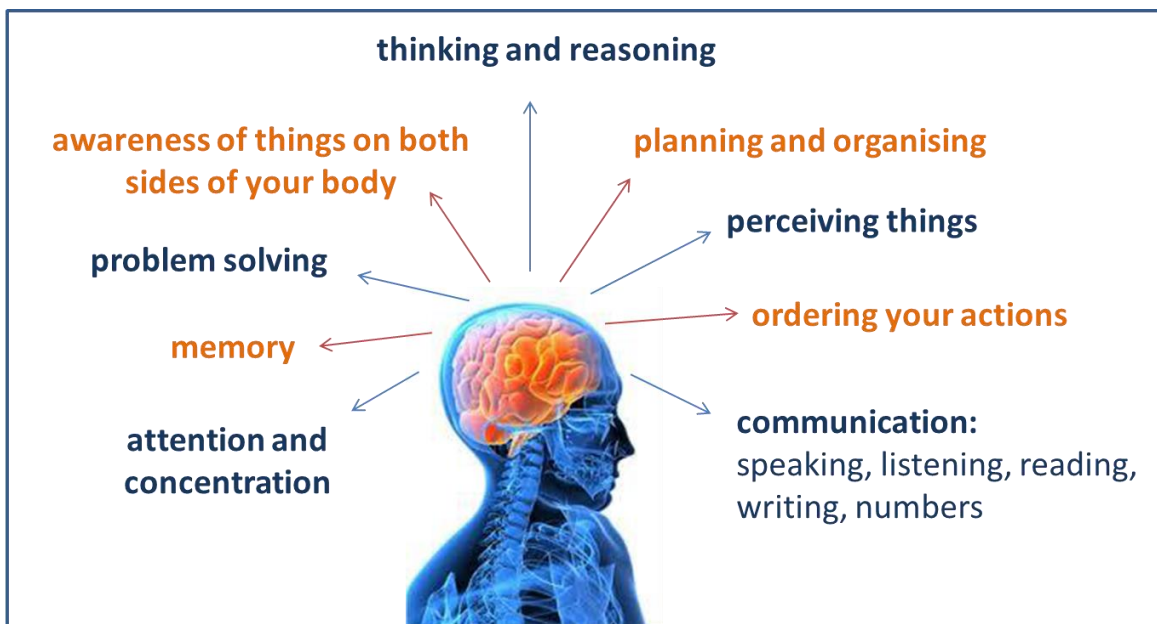
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Introduction

What is cognition?

Cognition describes many things to do with the **mind.** Cognitive functions help us to **think and understand the world**:


Why is it important?

Many stroke survivors have problems with **cognition**. These problems can last for a long time after stroke. They can affect peoples' **confidence** and **mood** as well as the **ability to recover** from stroke. We need to find **treatments** to **improve the lives** of people with cognitive problems after stroke.

What does a measure have to do with it?

Measures help us to **understand the effect** of treatments. This is important to help us **find out if a treatment has worked** or not.
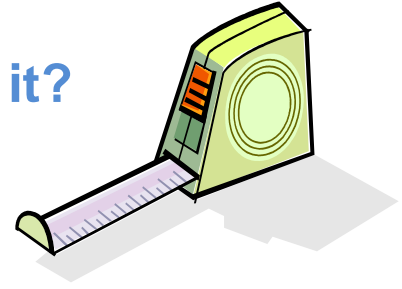
There are **many ways to measure** the effects of treatment.

One way is to ask stroke survivors themselves about the **impact of cognitive problems** and **whether they think a treatment has worked** for them. Their opinions on treatment can be collected using **Patient Reported Outcome Measures**.

People with cognitive problems are rarely involved in **designing and using these types of measures**. This means that there may not be any **Patient Reported Outcome Measures** that are **suitable for people with stroke and cognitive problems** to use.

Aim of the research

We wanted to find out whether there are any **Patient Reported Outcome Measures** that are **suitable for people with cognitive problems** to use.

If no **Patient Reported Outcome Measure** was suitable, we wanted to design a **new one**.

We **asked stroke survivors and carers to help us** plan and carry out all parts of the research.

The stages of the research

We carried out the research in **different stages.**

Stage 1: we **interviewed** stroke survivors with cognitive problems to ask **their opinions** on what should a Patient Reported Outcome Measure look like.

Stage 2: we **reviewed** Patient Reported Outcome Measures 'out there' to see if any were **suitable**.

At this stage, we found that **no measures were suitable** so

in **Stage 3** we **designed a new** Patient Reported Outcome Measure.

Then in **Stage 4** we **tested the new measure.**

Stage 1: Interview study

What we did

16 stroke survivors with cognitive problems took part in **interviews** with researchers.

Other stroke survivors with cognitive problems helped us decide **what questions to ask.** They also **helped design communication aids** to support people **to make their points.**

The **16 stroke survivors in the interviews** talked about:

- The **impacts** of their cognitive problems.

- The **important things to include in a Patient Reported Outcome Measure** to tell whether a treatment for cognitive problems had worked.

What we found

Stroke survivors said that **cognitive problems** had a **big impact** on their life and the **lives of their carers**. They said that a **Patient Reported Outcome Measure should:**

Ask about my **mood**

Ask about my **family and social life**

Ask about the **effect on my carer**

Make the questions **easy to read and understand**

Don't just ask if I have a problem. Sometimes I have a **problem that I can cope with**. You should ask me **if I am bothered by the problem.**

These findings meant we could write **recommendations** about what a **Patient Reported Outcome Measure** should **include and look like.**

Stage 2: Review of measures

What we did

We wanted to find **Patient Reported Outcome Measures** that were already 'out there' and being used by people with **cognitive problems**. We wanted to see whether any of them **met all the recommendations** from the **interview study.**

We searched **research papers** and **asked experts** to **help us find measures.**

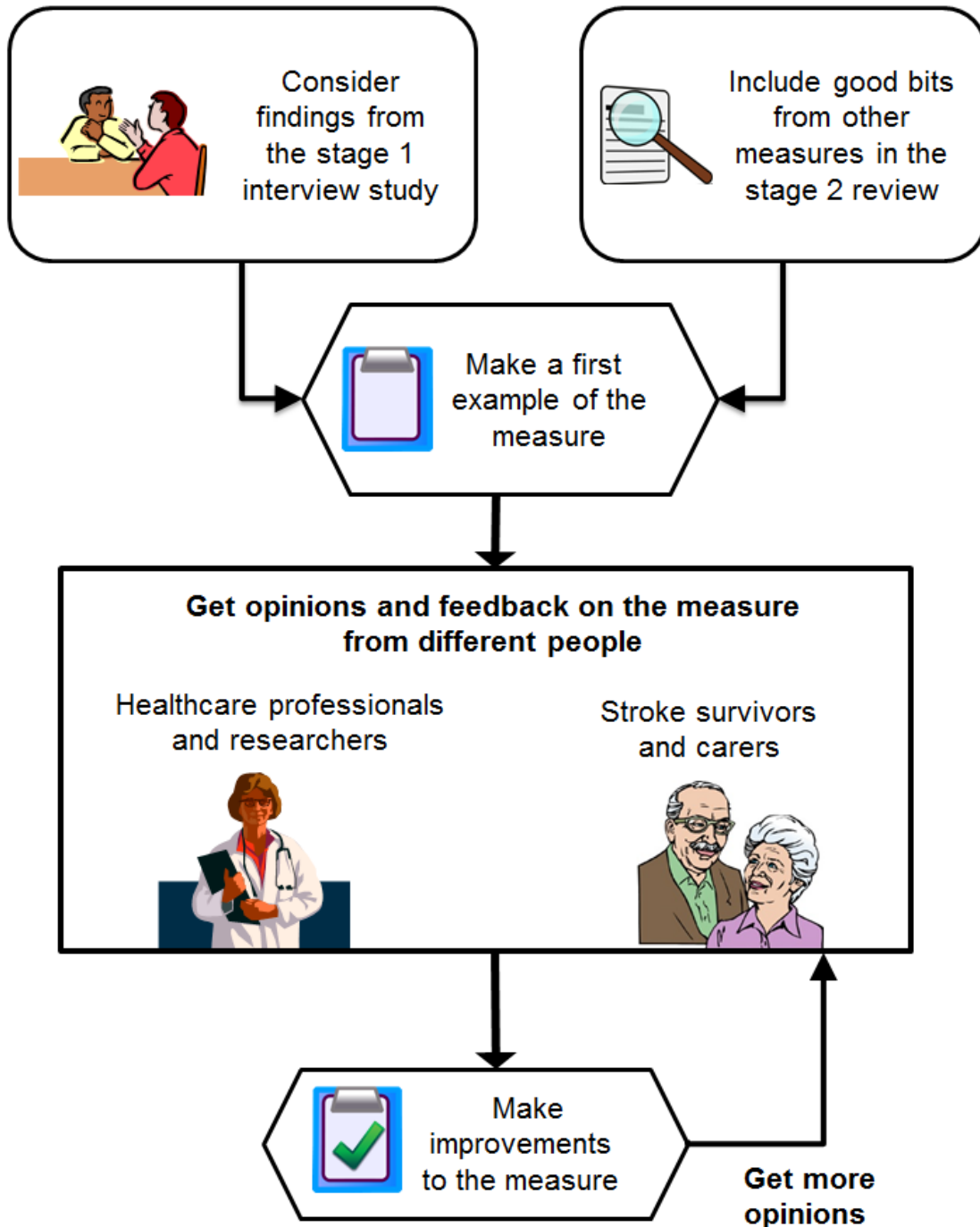## What we found

We found **20 measures** to review.

None of them **met all** of the **recommendations** that **stroke survivors** had spoken about in the **interview study**.

This meant that **no measures would be suitable** to use with stroke survivors who had cognitive problems. So the next stage was to **design a new measure.**

Stage 3: design a new measure

This picture shows the **process** of designing the new measure:

Consider findings from the stage 1 interview study	Include good bits from other measures in the stage 2 review

Make a first example of the measure

Get opinions and feedback on the measure from different people

Healthcare professionals and researchers

Stroke survivors and carers

Make improvements to the measure

Get more opinions

Stage 3: design a new measure

After making **a lot of changes and improvements**, we had a **final version** of the measure.

It was called the **Patient Reported Evaluation of Cognitive State.** This name is **shortened** to **PRECiS.**

PRECiS has **27 questions**.

These questions ask stroke survivors to rate the impact of cognitive problems on:

- **skills and activities**
- **mood** and **emotions**
- **family** and **social life**
- **self-esteem**

Each question has **2 parts**:

1. stroke survivors say **whether or not** they have a problem
2. If they do, they **rate how bothered** they are by that problem

PRECIS will soon be **available to view** through the University of Manchester website at:

http://www.click2go.umip.com/i/coa/precis.html

Stage 4: test the new measure

Aim

To test the new measure, PRECiS and see if it is:

- **Acceptable** – This means that stroke survivors find the measure **easy to use** and **understand.**

- **Valid** – This means that the measure is a**ctually measuring what we think it should**.

- **Reliable** – This means that the measure gives us **results we can trust.**

What we did

159 stroke survivors and 89 carers tested **PRECiS**.

Stroke survivors completed PRECiS **for themselves with support** from a researcher. Carers separately completed PRECiS to see if their answers **matched** those given by stroke survivors**.**

Everyone **gave feedback** on their experience of using PRECiS.

They also completed **other measures** about their mood and daily life. This helped us **compare results** from all the measures to see if responses were as we expected.

Some people completed PRECiS **a second time**. A **reliable measure** would give **similar results both times**.

What we found

- The measure was **acceptable**

S**troke survivors and carers liked the measure**. Most found it easy to understand. However, carers found it **hard to match the answers** of stroke survivors. This means that we should not ask carers to complete PRECiS in future.

- The measure was **valid**

When we compared ratings on PRECiS with ratings on other measures, **we got the results we expected**.

- The measure was **reliable**

All the items of PRECiS appear to be **measuring a similar thing**. When stroke survivors completed the measure a second time, **they gave similar responses**. This is a **good sign** that the measure is reliable.

Overall, PRECiS has some good qualities for **measuring the impact of cognitive problems on the life of a stroke survivor**.

What happens now?

We need to do some **more testing** of the new measure to**:**

- **shorten it**

- make it **easier to complete**

We also need to **publish the measure** in **scientific reports** so that others can find out about it easily.

Once we have done more testing, we hope that other people will start to **use the new measure in their research**.

It will be useful to get **stroke survivors own opinions** on whether **treatment for cognitive problems has worked** for them.

It will **help us understand** which treatments are good.

We hope that it will help **improve the lives** of people with cognitive problems after stroke.

There will be **detailed scientific reports available soon**.

You can **contact the lead researcher, Emma Patchick** to find out more about this.

Thank you to everyone who played a part in this study. Special thanks to Steve Hall, Victor Wright and Jean Wright who helped to make this book easier to read.

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