

# **Wellbeing After Stroke (WATER S-2)**

Project Report  
(accessible version)

Written with the help of stroke survivors

Research leads: **Dr Emma Patchwood** and **Professor Audrey Bowen**



If you would like to **hear** the contents of this booklet **read out loud**,  
or  
**watch** a brief video describing the project please **visit**:

<https://www.youtube.com/@watersstudy>



If you would like to see a 1 page poster that *very* briefly summarises this  
booklet and the project, you can view it here:

[bit.ly/WAterS2\\_poster](http://bit.ly/WAterS2_poster)



## What is this report?

This is a brief, accessible report on the ‘**Wellbeing After Stroke-2**’ project or ‘**WATERs-2**’ for short.

It **summarises** some key points about **what we did, what we found** and **what’s next**.

## Why have I received this report?

You have received it because you:

- **took part** in the project  
or
- **expressed an interest** in the project or in stroke



If you have any **questions** about this report or need **support to understand it**, please **contact us** using the **details below**.

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## Key words and phrases used in this report (1)

### **ACT**

Acceptance and **C**ommitment **T**herapy or **ACT** is a therapy for emotional wellbeing usually delivered by a clinical psychologist. This project is based on ACT.

### **Clinical psychologist**

**Trained** health professionals that provide **therapy** for people with **emotional distress**

### **Commissioners (NHS)**

The people responsible for **purchasing health services** within the NHS

### **Ethnicity**

and

### ***ethnic communities***

One way of describing people's background.

In this project, people chose how they wanted to describe their ethnicity using standard UK categories. We include this because reaching **ethnic communities** — *groups less represented in UK research and services* — was important in this project.

## Key words and phrases used in this report (2)

### **Mood**

How someone is **feeling emotionally**, such as feeling low, anxious, calm, or content. We know that wellbeing is about more than mood. In this project, mood and adjustment after stroke were the main focus.

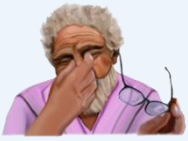
### **RAP**

The **Research Advisory Panel (RAP)** is a group of stroke survivors and other members of the public, from a range of different backgrounds, who have **helped with all aspects of the project**.

### **WAterS-2 project**

The name of **this project**. It stands for **Wellbeing After Stroke 2**; it is the 2<sup>nd</sup> WAterS project.

## Introduction



Stroke often affects emotional **wellbeing**. It can bring **distress** and cause **difficulties adjusting**.

Helping people **come to terms** with life after stroke is a **high priority** nationally, but there has been very little guidance about how best to do this. This is because:

- We don't know **what support** might help.
- This kind of support is often delivered by **Clinical Psychologists**- but there are **not enough** of them.



In 2019 the first Wellbeing after Stroke project (**WAtErS-1**), was set up to try to **understand how to improve support** for wellbeing after stroke.

In WAtErS-1 we:



- developed an **online, group therapy** for wellbeing after stroke
- developed a **training package for staff** who would run the group

WAtErS-1 showed promising results. The stroke survivors who took part enjoyed it and found it valuable

We successfully **applied for funding** to move on to the **WAtErS-2** project



Visit <https://sites.manchester.ac.uk/waters2/> to read more about **WAtErS-1 and its findings**

## What is WAterS-2?

In 2023 the **WAterS-2 project started**.

The main purpose of WAterS-2 was to **make improvements** to the **online group therapy** and the **staff training**.



We wanted to answer some **questions**:

1. Can we train **NHS staff** who are **not clinical psychologists** to lead the online group therapy sessions?
2. Will **enough stroke survivors**, including people from **ethnic communities** and people with **communication difficulties**, sign up?
3. Can we run online group therapy sessions **as planned** and **are they safe**?
4. What are **stroke survivors' experiences of the online group therapy sessions**?
5. What are **staff experiences of training and running the online group therapy sessions**?

## Who ran the WAtErS-2 project?

**Researchers** at the University of Manchester **led** the project and worked closely with **other experts** including:



- **Healthcare professionals** from the NHS

- **Clinical Psychologists** experienced in providing **support** for wellbeing after stroke



- **Experts by experience-** the Research Advisory Panel (RAP)



- The **Stroke Association** who also **funded** the project



Visit <https://sites.manchester.ac.uk/waters2/research-team/> to read more about who ran the project

## The Research Advisory Panel (RAP)

The **RAP (research advisory panel)** worked alongside the research team throughout the project.



Meet the RAP. The panel met regularly throughout the two and a half years of the project

The RAP included:

- people with **lived experience of stroke**
- people from a range of **ethnic backgrounds**
- people with experience of **communication difficulties** post-stroke
- people with **experience of supporting** a stroke survivor
- **community leaders / health champions**



Throughout the project we also **consulted** with:

- **stroke survivors at communication groups**
- individuals from **ethnic backgrounds**

Together they **helped design and run** the project. They helped make sure we used **understandable and accessible language**



Visit <https://sites.manchester.ac.uk/waters2/patient-carer-and-public-involvement/> to read more about our involvement team and strategy

## The development stage

**Firstly**, we needed to understand **how to improve** from WAterS-1. We:



- **interviewed** health professionals, service managers and commissioners
- talked with the **RAP**, **stroke survivors at communication groups** and individuals from **ethnic backgrounds**.



This helped us decide **what changes** would make the online groups **easier to access** and more **relevant** for:

- people with **communication difficulties** or
- people from **ethnic groups**.

The changes included:



- the **words** we used to talk about the groups
- **posters, information, and videos explaining the project**
- the **other resources** that support the groups, like **workbooks**

**The groups were carried out in English.**

Unfortunately this **limited who could take part** in the groups.



Visit <https://sites.manchester.ac.uk/waters2/> to read the scientific paper on the interviews from this stage

## What is the group therapy?

The groups are based on an existing therapy called **Acceptance and Commitment Therapy** or '**ACT**'

ACT was designed to help people **come to terms** with difficult situations



- The groups were adapted to be delivered over **8-weekly sessions**



- Each session was **2 hours long** with **breaks**

- We used an **online platform** called "Teams"



- We **revised resources** to make the groups more accessible including a **user workbook**

- Stroke survivors were encouraged to complete '**home practice**'

- We used **tools** and **strategies**. Some are listed on the next page.

The **tools** and **strategies**, included:



**Tips** to work around **common issues after stroke**:  
forgetting, word-finding problems, and tiredness.



Work with **core values**.  
These are the things that **matter to us**



Practices to help people ‘**drop anchor**’ in the moment;  
called **mindful noticing** and **mindful breathing**



Introducing **helpful ways to think** about our feelings



Setting **goals** to **plan for the future**



Visit <https://tinyurl.com/FindoutmoreACT> to learn more about ACT

## What is the staff training?

Staff training and support included:



- 4 half-day **training** sessions delivered **online**
- Weekly guidance from a **Clinical Psychologist**
- Specially prepared **resources**, such as an **instruction manual** with 'scripts'



## Testing the WAtErS-2 groups

This involved running 4 online WAtErS groups across England to find out how it worked in practice, with a range of people.



This was a small project. Its purpose was to explore **if it would be useful** to do a **bigger project in the future**. This helps us understand:

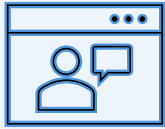


- if it should be tested more and
- how future projects should be designed.

This is a way of making sure we **invest time and money wisely**.

## How did we collect information?

We collected **different types of information** in this project:



We first collected **information** about people by **phone** and **online**



People completed **online surveys** about their experiences, mood and wellbeing.

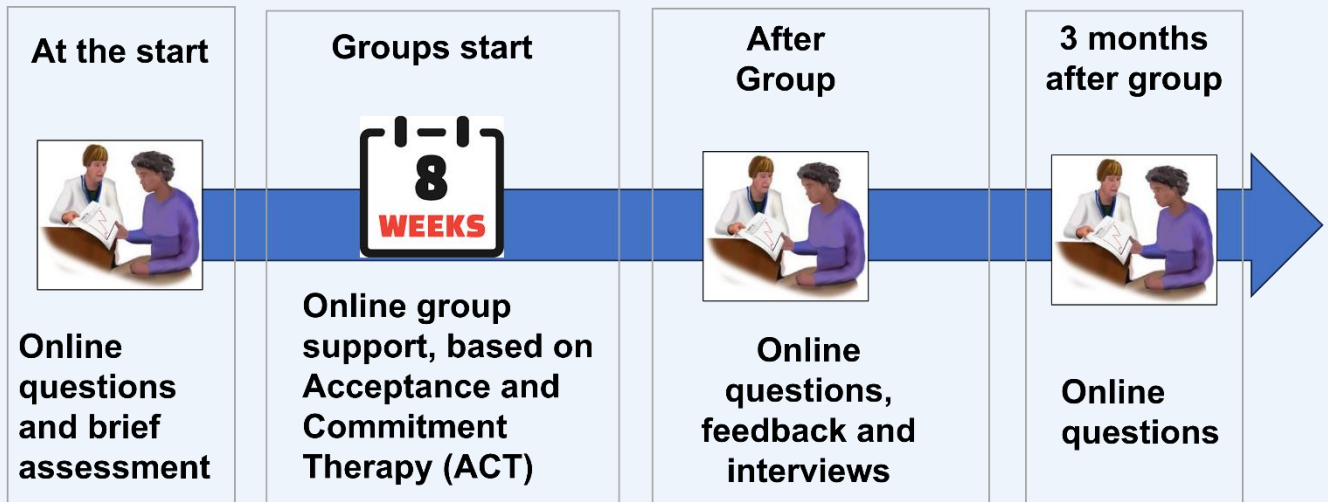


We **spoke to people** in one-to-one, online **interviews**. This helped us **understand more about their experiences**



We took **video-recordings** of **staff training** sessions and **WATERs group sessions** with stroke survivors. This meant we could **check** if sessions had **gone as planned**.

The diagram below shows **what was involved** for **stroke survivors** and what **information** was **collected** from them at each stage.



## Who took part? Stroke survivors

- **31** stroke survivors were **interested** in **finding out** about the **groups**
- **19** stroke survivors joined WAtErS groups
- The groups included **between 3 and 7 stroke survivors** and were led by **2 or 3 trained staff**



Of the **19 stroke survivors** who joined groups:



**12** were male



**7** were female



The **youngest** was **23** and the **oldest** was **81** years old

### Ethnicity

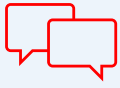


**14** White or White British

**2** Asian or Asian British

**1** Black, Black British, Caribbean or African

**2** Mixed or multiple ethnic groups



**About half** of the stroke survivors had some **communication difficulties** because of their **stroke**



Stroke survivors joined the groups **between 4 months to over 3 years after their stroke**



Overall, when joining the groups, people had **some difficulty** with **mood** and **adjusting** since their stroke

**After the groups finished, of the 19 stroke survivors who took part:**



**15** completed **online questionnaires**

**13** people invited took part in **recorded interviews**



## Who took part- Staff

We trained **13 staff**. They were not clinical psychologists



**12** were female



**1** was male

It is quite typical to see more females than males in these roles



**12** worked for the **NHS**; **1** worked for the **Stroke Association**

**Staff roles** included:

- **Physiotherapists,**
- **Occupational therapists**
- **Rehabilitation assistants**
- **Peer support workers (with lived experience of stroke)**

Staff had between **1 and 15** years of **experience** working in **stroke**.

Staff had **no experience** of delivering **Acceptance and Commitment Therapy (ACT)** to **groups**

**All 13** staff completed online questionnaires:



- **after the training** and
- **after the groups**

**All staff** took part in **recorded interviews**



## What did we find? (1)



The project has answered the following questions:

1. Can we train **NHS staff** who are not clinical psychologists to lead the online group therapy sessions?

### YES!

- All **13 staff** were **trained** and **took part in running group sessions**
- It was **novel** that we could **train peer support workers (stroke survivors) to deliver this group**
- The groups were **completed as planned**
- **Staff told us they will continue to use ACT**



“I could see how little snippets of it - like the mindfulness videos – I could do that in some of my [one to one] sessions”

### BUT

- Some NHS locations wanted to take part but **could not**, due to **work pressures**

## What did we find? (2)

2. Will **enough stroke survivors**, including people from **ethnic communities** and people with **communication difficulties** sign up?

**YES**



- The groups included people from **ethnic backgrounds**, and people with a **range of communication difficulties**.
- This range is often missing in other stroke projects
- Staff and stroke survivors felt the **groups were inclusive**

“Background is not the problem... Brown, black, white. It doesn't matter”

- **Most** people felt the **groups and materials** were **accessible**



## BUT



- We could **only** include people already **within NHS services**. This meant it was **still inaccessible to some communities**.
- Also, we could **only** conduct groups in **English** which meant **people who did not speak English were unable to take part**

*"We don't... use translators for our groups either, so we're automatically missing people"*

*"We didn't get many women from ethnic minority groups"*

**There is still a lot of work to be done.**




Some people with **communication difficulties** were **unable to fully take part**

*"I can understand... but I can't... communicate what I wanted to say"*

## What did we find? (3)

### 3. Can we deliver **online** group therapy sessions **as planned** and **are they safe**?

#### YES

- Online sessions were **completed as planned** 
- There were **no safety issues**
- Staff told us that having a **Clinical Psychologist to support** them was important

“If I was delivering this without having that kind of person to reach out to, I’m not sure I’d feel as safe... it does need to have some psychology oversight”

## BUT

- Staff told us that some of the groups **finished early**; and some had **too much content**

*"It was long... I don't know whether it would have been better in smaller chunks. It just felt like they were long"*

- Staff felt it would be **easier** to run the groups "**next time**" after some practice

*"Now I've done it once... I'd be happy to do it again and do a bit more"*

## What did we find? (4)

### 4. What are **stroke survivors' experiences** of the online group therapy sessions?



- **Most** people got something **positive** from the groups.
- **14 out of 15** would recommend it to others
- Many people found the **workbook helpful**
- **13 out of 15** said they would **keep using** some of the **strategies** they learnt



*"When I'm feeling a bit anxious, I close my eyes and I concentrate on my breathing. I will always do that"*



- **14** people said that **online was suitable BUT** many people would have **preferred** the groups to be **face to face**

*"People would have opened up a bit more [face to face]."*

*"I think that just makes it more accessible for everybody else, because we...couldn't all got together any [other] way."*

- People found the **support from others** in the group **helpful**

*“I’ve found myself able to open up a little bit more... just the fact of being in the programme itself... and hearing others open up”*



- There was **no agreement** about **how soon after stroke** people should be offered the groups

## What did we find? (5)

### 5. What are **staff experiences** of **training** and **running** the **online group therapy sessions**?

- **All staff** found the **training, supervision and resources helpful**

“The resources are amazing... I feel very lucky”

- They found many of the **ACT techniques helpful** and will **continue to use them**
- They felt that **many people benefitted** from the groups, but **not all techniques worked for everyone**



“He didn’t connect with some of the analogies... but he did like the breathing...”



- There were **mixed feelings** about running the groups **online**
- Staff felt that **8 x 2 hour groups may not be possible** in current NHS work settings

“In its current format, no. But... if the format was slightly different or tweaked. Then yes... I think ACT... could be used 100%...”

“So I suppose the need is there but our resources are not there”

## What does this mean?

1. Stroke survivors **could benefit** from online group therapy at **different times after their stroke**
2. It **may be difficult** to run online WAtErS group therapy sessions **within the NHS**

### however:

- We showed that **trained peer support workers** could deliver WAtErS-2.
- **Non-NHS services** e.g. charities, may be **better able to deliver** WAtErS online group therapy sessions
- **Further work** is required to help us reach **different communities** including exploring if:
  - **community groups** could be **supported to deliver** sessions within their trusted communities.
  - groups should be delivered in **different languages**
- ACT techniques would be **helpful additions** to both staff and stroke survivor's "tool boxes" of skills

## What happens now?

WATERs-2 is **complete**. We **answered the project questions** and have **learnt a lot**.



We plan to **share our findings locally and internationally** with clinicians, researchers and others interested in stroke rehabilitation.

We still have a lot more work to do and we:



- have secured funding to **develop WATERs further**
- are writing articles to **raise awareness** and share our findings
- will make the **resources** we develop **freely available**
- are working **with others** to **engage better** with those **outside NHS services**

## How can I find out more?

If you have **any questions** about **the project** or **about getting involved in research**, you can contact us on:



**0161 275 3401** (for Emma Patchwood)



**waters@manchester.ac.uk**

Detailed scientific report **available soon**. This will be **added to the website** at: <https://sites.manchester.ac.uk/waters2/>



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... to **everyone** who played a part in this project.

Special thanks to the **WATERs Research Advisory Panel**, who helped to make this report **easier to read**.

The group consists of: Ann Bamford, Rudolph Edwards, Billy Ellison, Sanya Karim, Jav Rehman, Wendy Simms, Stephen Taylor

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**Stroke**  
Association

You can find out more about the Stroke Association on this website:  
[www.stroke.org.uk](http://www.stroke.org.uk).

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