

Wellbeing After Stroke (WATER-2)

**Project Report
(accessible version)**

Written with the help of stroke survivors

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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>



What is this report?

This is a brief, accessible report on the ‘**Wellbeing After Stroke-2**’ project or ‘**WATER-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 study, 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 an important part of this study.

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 study, mood and adjustment after stroke were the main focus.

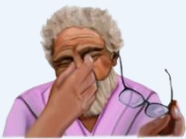
RAP

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 study**.

WAterS-2 project

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

Introduction



Stroke often affects emotional **wellbeing**. It can bring **distress** and causes **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 develop it in 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

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 study 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/> to read more about **patient, carer and public involvement in research**

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 to change** to make the online groups **easier to access** and more **relevant** for:

- people with **communication difficulties** or
- **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:

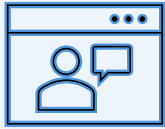


- if it should be tested more and
- how future projects should be designed.

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.

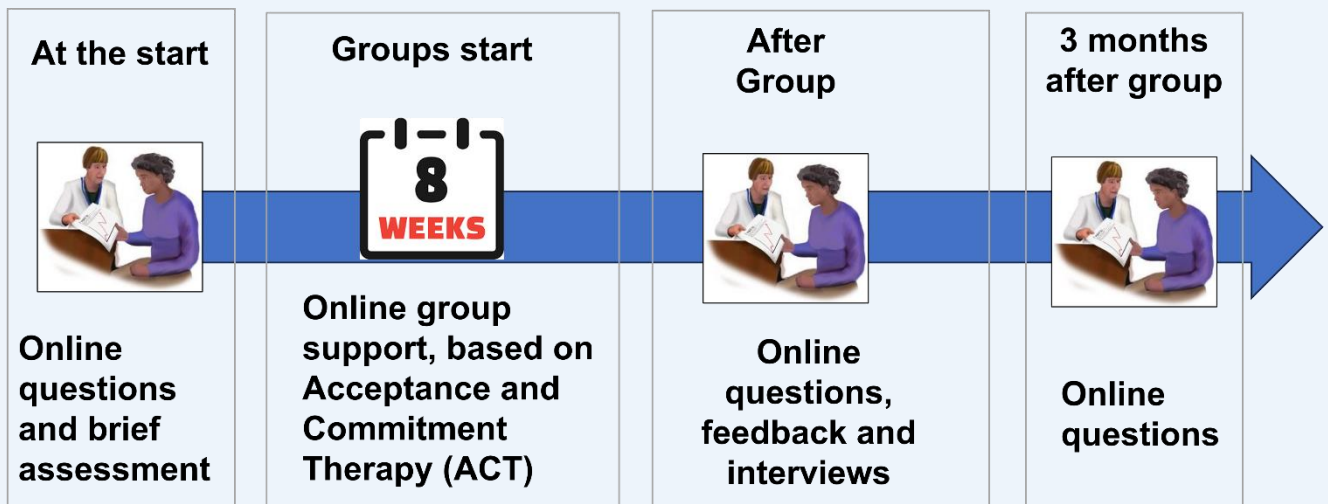


We **spoke to people** in one-to-one, online **interviews**.
This helped us **understand more about their experiences**



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

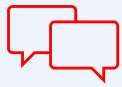


14 White or White British

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?

WATER-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 WATER further**
- are writing articles to **raise awareness** and share our findings
- **are developing resources** so these can be made **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
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You can find out more about the Stroke Association on this website:

www.stroke.org.uk.

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