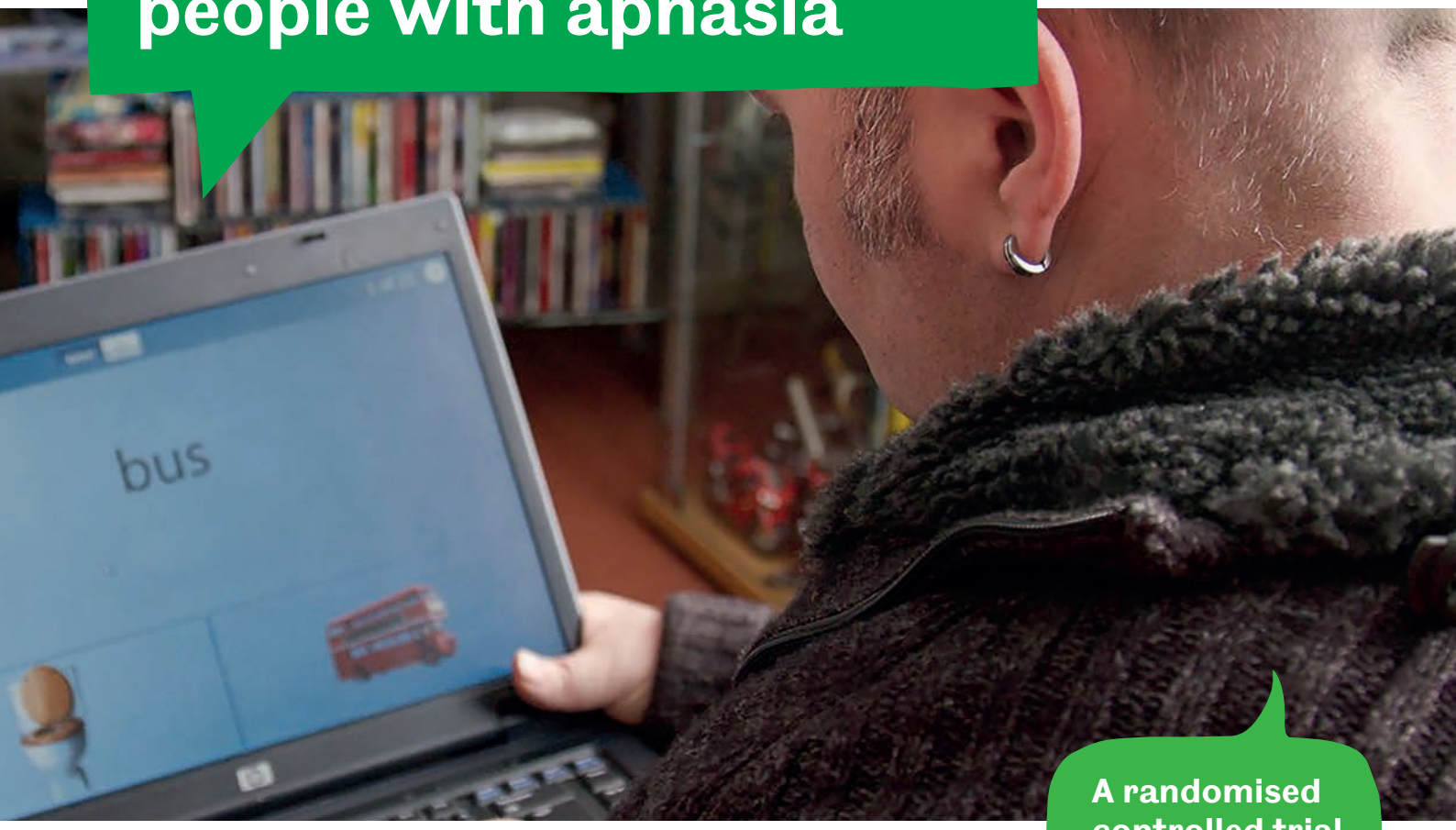
The University Of Sheffield.

Big CACTUS

The findings of a study of self-managed computer therapy to help word finding for people with aphasia



A randomised controlled trial

2018

The full report will be publicly available following peer review at www.journalslibrary.nihr.ac.uk/programmes/hta/122101. A film of the results will also be available on this website.

The Tavistock Trust for Aphasia

Funded by NHS National Institute for Health Research

Overview

Aphasia is a **language disorder** which can make it difficult for people to **talk, understand, read and write**. Currently, **speech and language therapy for aphasia** more than 4 months following a stroke is often **limited**. Where it is available the amount of therapy is often lower than amounts that have been shown to be the most effective. **A lot of people with aphasia want more therapy** than they receive. We offered people with aphasia the opportunity to do **self-managed speech and language therapy for word finding** using a **computer** at home. This was in addition to the face to face speech and language therapy available to them. We found:

1. Self-managed **computer therapy** tailored by a speech and language therapist and supported by speech and language therapy assistants or volunteers **increased the amount of speech and language therapy** provided. **(Pages 16 & 17)**

2. People with aphasia **improved their ability to find words** with the addition of computer therapy. These improvements lasted for at least **6 months after the therapy** had ended (therapy may have only lasted for 6 months but participants could continue to use the computer for longer). **(Pages 18 & 19)**

3. People with aphasia made **improvements at any time post stroke** (4 months to 36 years in the Big CACTUS study). It did not matter how long ago the stroke happened. **(Pages 18 & 19)**

4. Most people with aphasia **did not** automatically use **newly learned words in conversation**. However, one third of people with aphasia did use more words in conversation. More practice of the words may be needed in everyday contexts. **(Pages 20 & 21)**

5. People with aphasia **did not** indicate significant **improvements** in their **everyday communication** or **quality of life** on a rating scale. **(Pages 20 & 21)**

6. **Carers did** notice small **improvements** in the **communication of the people with aphasia. (Pages 20 & 21)**

7. The addition of this specific computer therapy approach was **unlikely to be cost effective** for **everyone with word finding difficulties**. **(Pages 24 & 25)**

8. The computer therapy approach was most likely to be **cost effective** for those with **mild and moderate word finding difficulties**. **(Pages 24 & 25)**

9. The computer approach to delivering more word finding therapy in the longer term post stroke was **relatively inexpensive**. It was **half the cost** of delivering the same amount of additional therapy **face to face** by a speech and language therapist. **(Pages 26 & 27)**

10. **Conclusions and the future**: People with aphasia can improve their word finding with extra practice provided at low cost by a computer therapy approach. This could be a useful addition to speech and language therapy services. It is important to encourage the use of new words in everyday communication to improve the overall quality of life. **(Pages 28 & 29)**

Who is this booklet for?

This booklet is for **everyone** who is interested in the findings of the Big CACTUS study.

The **left hand pages** of the booklet give detail about the project that may be of interest to speech & language therapists, service managers, commissioners and other people who would like detailed information about the study.

The **right hand pages** highlight **key points** about the **study**.

These are for **people with aphasia**.

Other people may wish to **read** these pages for an **overview**.

The focus of the Big CACTUS study

Our goal was to use computers to give people with aphasia the opportunity to have more speech and language practice.

What do we know about aphasia and what helps?

Aphasia is a language disorder acquired by more than one third of people after a stroke. Aphasia makes it difficult for people to understand spoken language, read, write or talk. It makes daily life, relationships, roles in the family, at work and in the community difficult and can lead to isolation and low mood.

Speech and language therapy aims to help people to improve their language ability and participate more fully in daily life. Speech and language therapy is usually offered in the early weeks and months after a stroke. However, **there is growing evidence that language improvement can continue months and years after stroke with more therapy** (Breitenstein et al, 2017).

How much speech and language therapy is currently provided to people who are more than a few months post stroke?

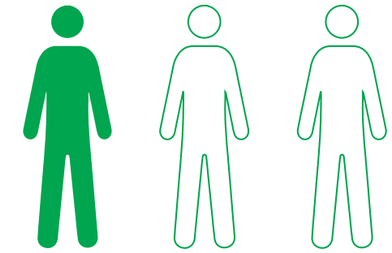
As part of the Big CACTUS study we observed how much speech and language therapy was provided in 20 NHS trusts in the UK. Therapy provision in the 3 months before each participant was included in the study was recorded. People with aphasia were between 4 months and 36 years post stroke. We found:

- **42% of people with aphasia were receiving speech and language therapy**
- Of those who received therapy, on average they received 5 hours 20 minutes over 3 months (1 hour every 2 weeks) – much less than suggested for best effect (Brady et al, 2016)
- People with aphasia were less likely to receive ongoing therapy if they had mild difficulties finding words

A recent survey in Northern Ireland showed that therapy stopped for 63% of people with aphasia by 3 months post stroke (Kennedy, 2018).

People with aphasia and their carers want more speech and language therapy. (Royal College of Speech & Language Therapists, 2008)

1 in 3 people have **aphasia** after a stroke



Talk

Understand

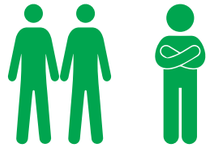
People with **aphasia** often find it **difficult** to...

Write

Read

This can lead to

Low mood



Isolation

People with aphasia often want more **speech and language therapy** than is available.

The computer therapy approach

The approach we adopted had 4 components:

1. Specialist aphasia software installed on a PC, laptop or tablet computer
2. A qualified speech and language therapist to tailor the software to the needs of the person with aphasia
3. Independent practice of the tailored exercises at home by the person with aphasia
4. Monthly support from a volunteer or speech and language therapy assistant

Speech and language therapists attended one-day training on how to deliver the computer therapy approach and were given a therapy manual, available here: **www.sheffield.ac.uk/scharr/sections/dts/ctru/bigcactus**

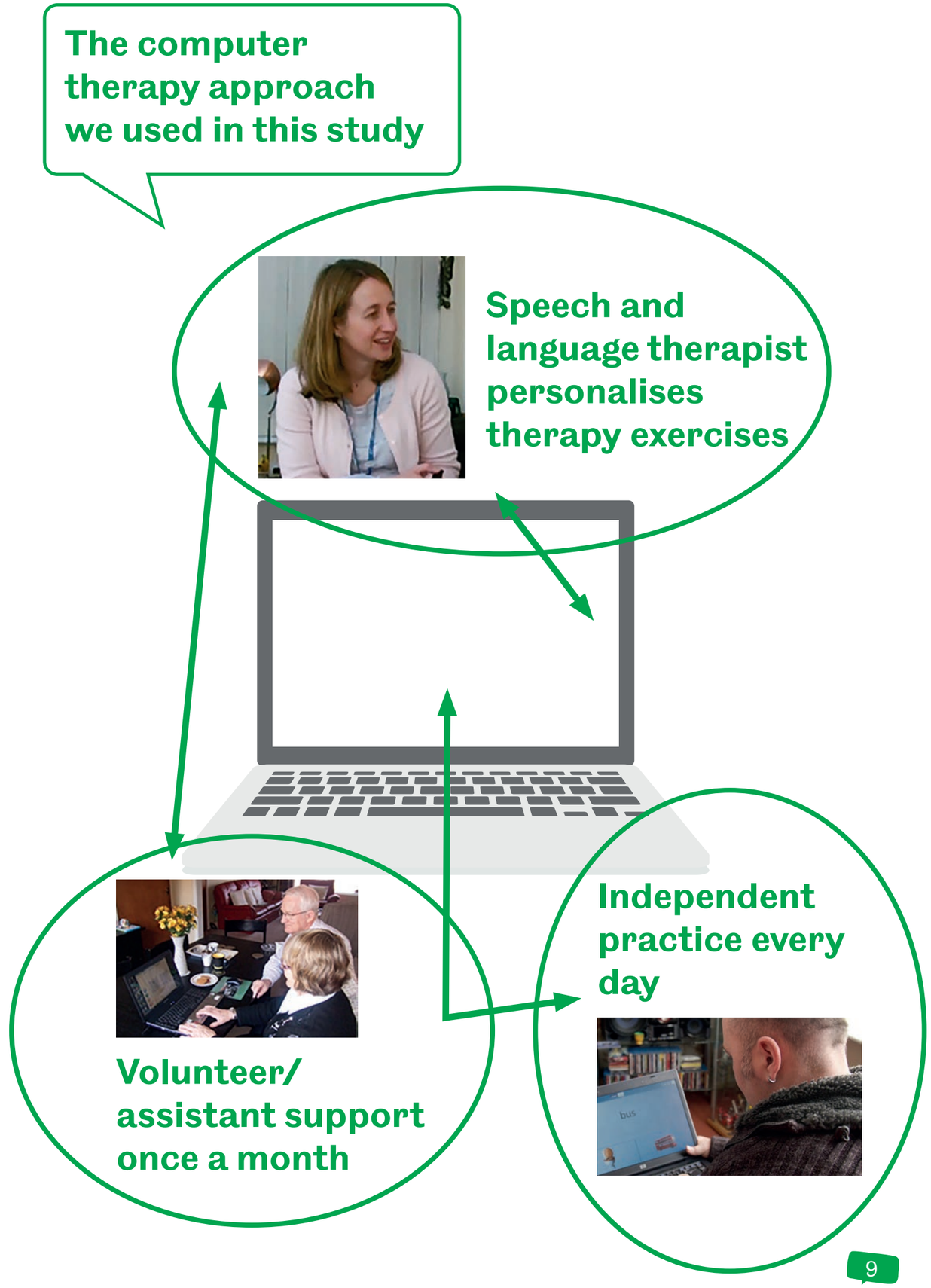
Difficulty finding the right words to say is common to the majority of people with aphasia so we chose to focus on this in this study. This is just one of the things people with aphasia need help with. In practice, many people with aphasia would be treated for reading, writing and understanding as well. These could also be addressed with specialist computer software.

We chose to use StepByStep © software version 5 as it allows the therapist to use words that are most meaningful to the person with aphasia; the therapist can select exercises that are likely to be most helpful to the individual. It provides feedback to the person with aphasia (using speech recognition technology) on whether they said the correct word. In the study the speech and language therapists asked each participant to identify 100 words that would be most useful for them to be able to say. They then tailored the practice exercises based on the abilities and difficulties the person with aphasia showed during language assessment.

The person with aphasia was encouraged to practise with the software exercises for 20-30 minutes a day over a 6 month period.

Volunteers or speech and language therapy assistants were trained by the speech and language therapists to provide support – 30 minutes every 2 weeks, or 1 hour each month. They helped the person with aphasia move on to harder exercises, practised using the new words in real contexts and fed back on progress to the speech and language therapist.

The software was put on the person with aphasia's own computer if they had one which was compatible with the software, or it was loaned on a laptop or tablet. If the person with aphasia had the software on their own computer or they were able to continue borrowing a computer, they could continue to use it after the 6 month supported period had come to an end.



What did we want to find out in the study?

We wanted to find out whether the computer approach to aphasia therapy for word finding...

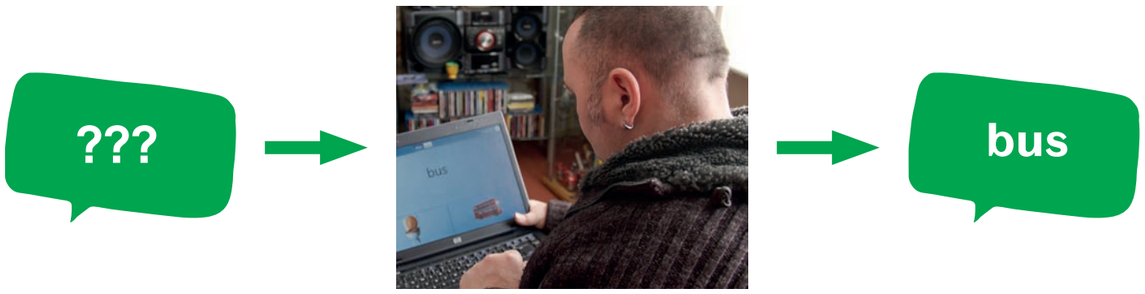
- Improves ability to find words chosen by the person with aphasia
- Improves ability to have conversations
- Helps people with aphasia be more involved in everyday communication and improves their quality of life
- Leads to improvements that are still there 6 months later
- Is cost effective for aphasia more than 4 months after a stroke

We also wanted to find out whether...

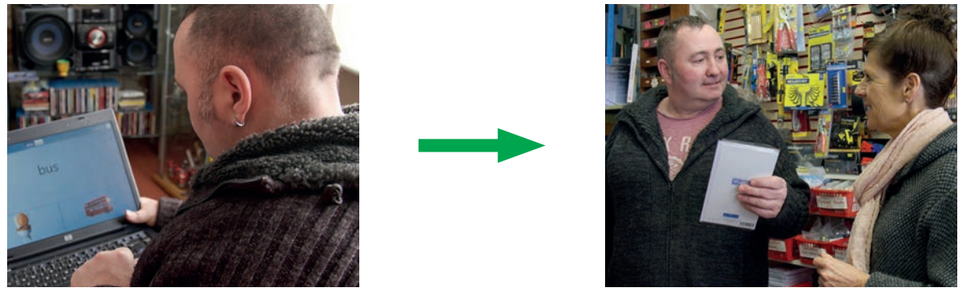
- People with aphasia use the words they specifically learned to say in therapy in conversation
- The word finding therapy helps people find words that were not specifically used in therapy
- Carers perceive that their relatives with aphasia are more involved in everyday communication and whether the therapy has any impact on carers' own quality of life

We wanted to **find out...**

If the **computer therapy** makes it **easier** to **find words**



If it helps **everyday communication** and **conversations**



If it is **good value for money**

How did we conduct the study?

We wanted to evaluate how the computer therapy worked when delivered in practice in the NHS. People with aphasia were recruited by speech and language therapists working in 20 NHS trusts in the UK.

The speech and language therapists carried out language assessments and checked the people with aphasia were eligible for the study.

Inclusion criteria	Exclusion criteria
• Aged 18 or over • Diagnosis of stroke(s) • Onset of stroke at least 4 months prior to randomisation • Diagnosis of aphasia, subsequent to stroke, as confirmed by a trained speech and language therapist. • Word retrieval difficulties tested by the naming test of the Comprehensive Aphasia Test (score of 10-90%). • Ability to perform a simple matching task with the StepbyStep© programme (to confirm sufficient vision and cognitive ability to participate in the intervention)	• Additional pre-morbid speech and language disorder caused by a neurological deficit other than stroke. • Unable to repeat words (suggesting presence of severe dyspraxia) • Require treatment for a language other than English (as the software is in English) • Currently using computer speech therapy aimed at word retrieval/naming.

We wanted to know whether our approach to using computers for therapy was effective in addition to available face to face speech and language therapy. Therefore, all people with aphasia in the study continued to receive speech and language therapy if it was available.

People with aphasia who were eligible were randomly allocated to one of three groups:

- Available speech and language therapy on its own
- The computer therapy approach in addition to available speech and language therapy
- Completion of puzzle books and phone calls from a researcher in addition to available speech and language therapy

The third group aimed to mimic the activity and attention received by those who had computer therapy. This was because we needed to know whether improvements with the computer therapy were because of the extra speech and language therapy or just because they were doing more activity and receiving more attention.

All therapy was provided by speech and language therapists working in clinical practice.

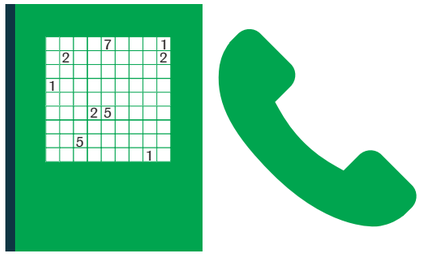
Speech and language therapists carried out language assessments at the end of therapy and also 3 and 6 months after the therapy had finished. These speech and language therapists did not know which groups the people with aphasia were in.

Specialist statisticians and health economists analysed the results.

People with aphasia joined the study from all over the UK

There were 3 **different groups** in the study

Computer therapy with **assistant/volunteer support**



Puzzle books and **phone calls**

Available speech and language therapy alone

All groups continued with **speech and language therapy** if available.

Who was in the study?

278 people with aphasia were recruited to the study

177 carers were recruited to the study

61% of the people with aphasia were men and 39% were women

The people with aphasia were between 23 and 92 years old (with an average age of 65.4 years)

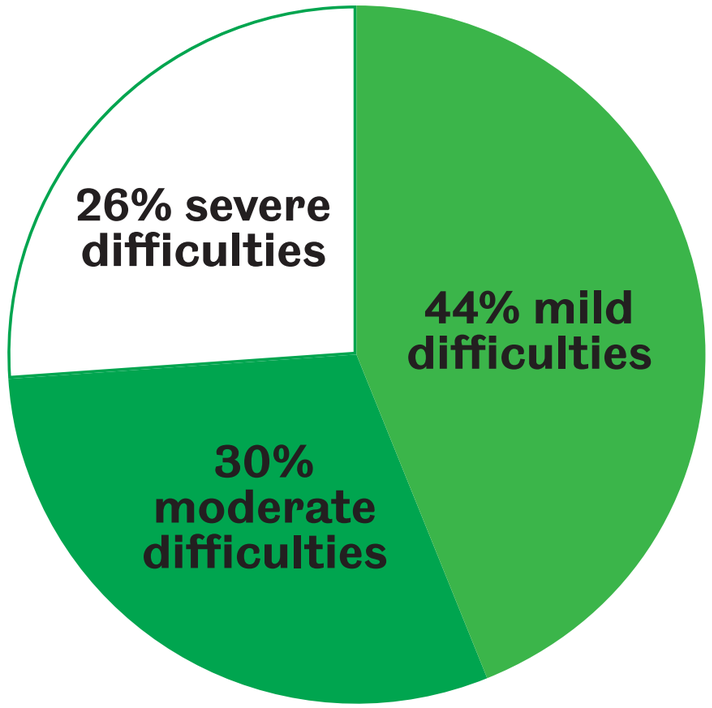
Severity of aphasia:

- 44% had mild word finding difficulties (defined as a score of 31-43 out of 48 on the object naming test of the Comprehensive Aphasia Test)
- 30% had moderate word finding difficulties (score of 18-30)
- 26% had severe word finding difficulties (score of 5-17)

The people with aphasia had their stroke between **4 months and 36 years** ago (with an average of 2 years ago).

278 people with aphasia and **177 carers** were in the study.

People had **different levels** of **word finding difficulty.**



Did people with aphasia take the opportunity to use the computer to practise finding their words?

People with aphasia practised finding words independently with the computer exercises for 28 hours on average.

- The amount of time people with aphasia spent using the computer to practise finding words ranged from 0 to 105 hours.
- About 90% of people with aphasia used the computer exercises they were given.
- 64% of people with aphasia used the software for more than 10 hours.
- 46% of people with aphasia used the software for more than 26 hours.

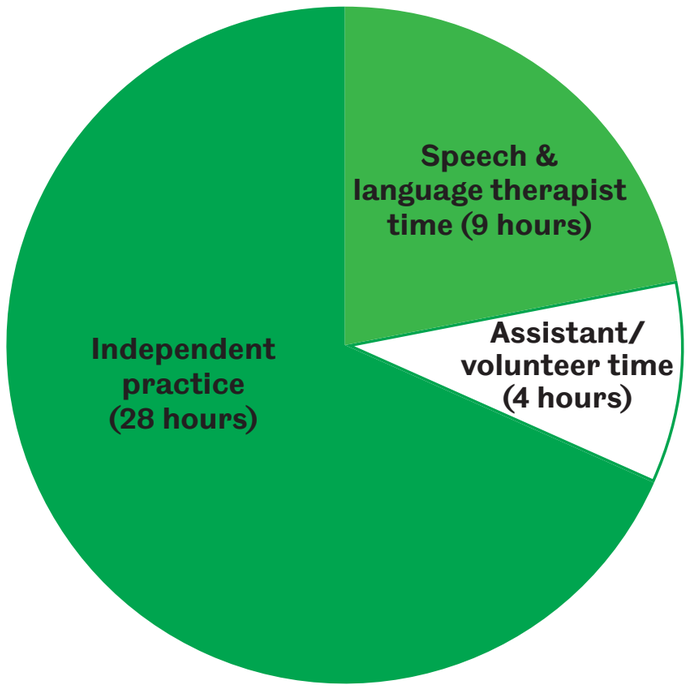
61% of the people with aphasia chose to continue using the computer for more than 6 months.

On average, a speech and language therapist spent 9 hours assessing the person with aphasia, tailoring the software to their needs and providing support.

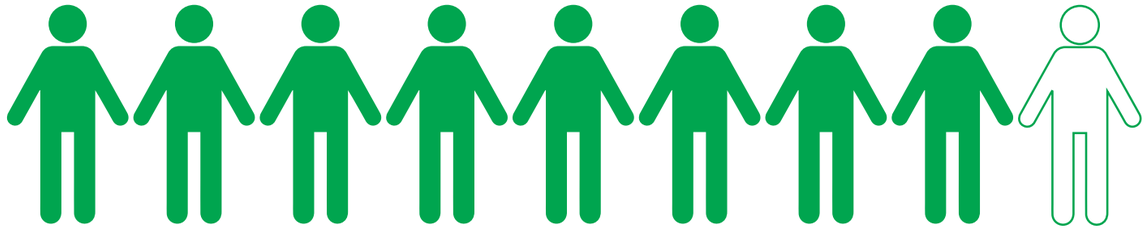
A speech and language therapy assistant or volunteer spent 4 hours supporting the person with aphasia on average.

Being supported to work independently with the computer exercises increased the amount of therapy practice for the people with aphasia.

A third of people with aphasia used their own computer for therapy practice and two thirds needed to be a loaned a tablet or laptop from their NHS trust. This is because the software only ran on Windows 7 and above at the time of the study.



90% of people used the **computer therapy** they were given.

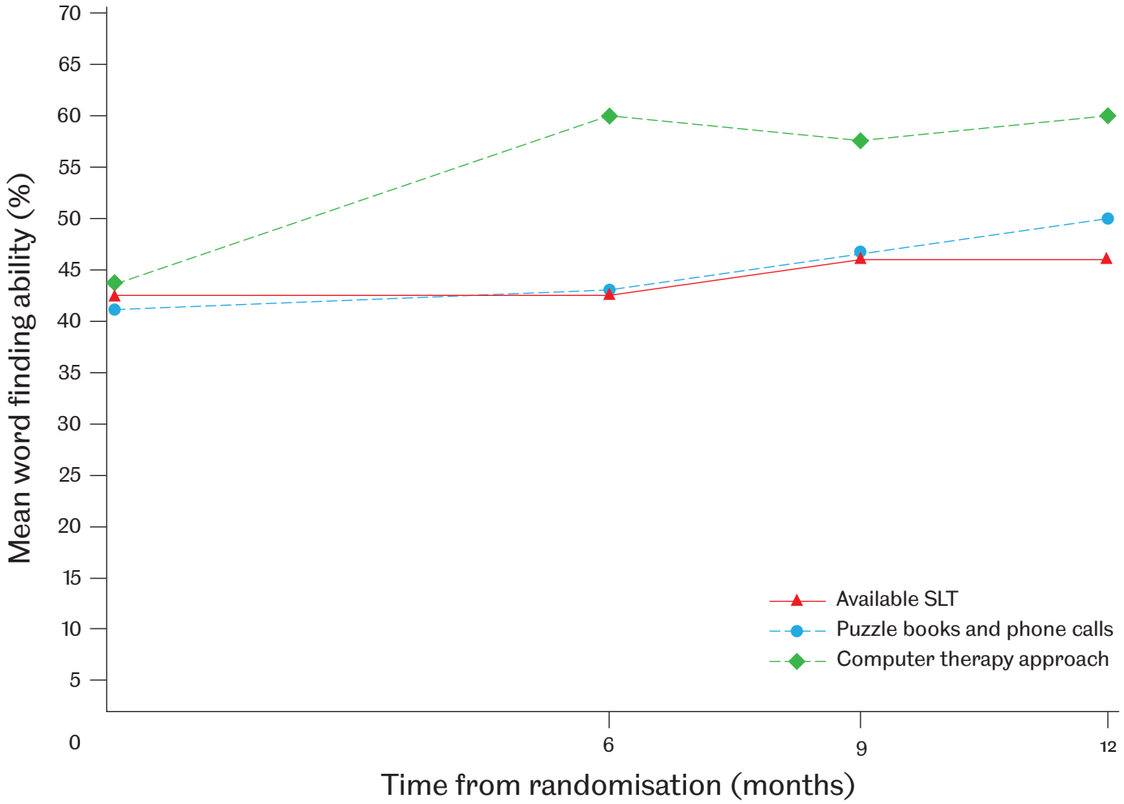


The **software** enabled people with **aphasia** to do **more therapy.**

61% of people used the computer for **more than 6 months.**

Did the computer therapy improve word finding?

The **computer therapy significantly improved the ability of people with aphasia to find words** they chose to learn. Those in the computer group improved by 16.2% more than those in the group having available speech and language therapy only (95% Confidence Interval (CI)12.7%-19.6%, P<0.0001).



The computer group also improved by 14.4% more than those in the puzzle book and telephone conversation group (95% CI: 10.8% to 18.1%). This suggests the improvement was caused by the speech therapy computer exercises rather than simply more activity and attention.

The improvements in word finding were still seen 6 months after the therapy.

People with aphasia were able to learn new words at any time post stroke. It did not matter how long ago the stroke happened (people in the study were 4 months to 36 years post stroke).

People who had mild aphasia made slightly bigger improvements.

Only 10 of the people with aphasia (out of 94 who had the computer) didn't show any improvement. There was no record of the amount of practice time for 3 of the people who didn't improve. Four used it for less than 5 hours. Three used it for between 20 and 68 hours.

Computer therapy helped people with aphasia **to learn new words.**

Computer therapy helped **no matter how long ago the stroke was.**

Did the computer word finding therapy help people with aphasia to have better conversations? Did they use the words they learned?

There was no evidence that the computer therapy for word finding helped to improve general conversation compared to available speech and language therapy alone (change of -0.03 (95% CI: -0.21 to 0.14; p=0.709)

The words learned in the word finding therapy were not automatically used in conversation by the majority of people with aphasia. However, 3 in 10 people with aphasia who used the computer word finding therapy did improve their use of the words in conversation by at least 5% (compared with 1 in 10 people who had puzzle books or available speech and language therapy only). This suggests that some people with aphasia automatically use the words they learn, but many do not.

It is possible that thinking of the correct word when it is needed in a real life context is a different or more difficult task than retrieving it during naming practice out of context. In addition, people who have had aphasia for many years may experience 'learned non-use'. In other words, they may have become used to using gesture and other methods of getting their message across rather than speaking and therefore do not automatically use the words when they can retrieve them again.

We need to consider how to help people with aphasia use the words they learn in everyday situations.

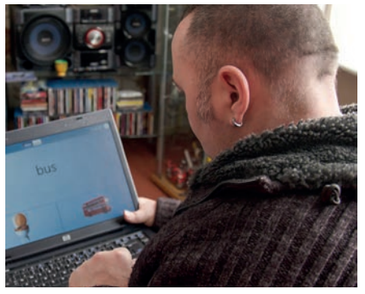
Did the computer word finding therapy impact on everyday communication and quality of life?

There was no evidence that people with aphasia perceived that computer therapy for word finding improved their everyday communication or quality of life more than available speech and language therapy alone. The computer therapy group only indicated a change of 0.5% more than those in the available speech and language therapy group (95% CI: -3.1 to 4.1).

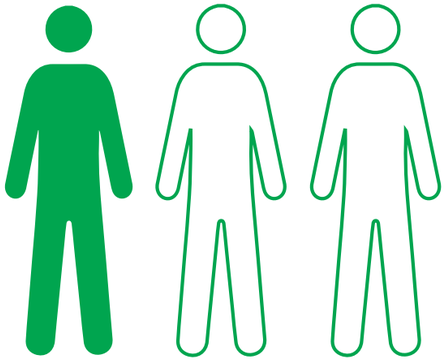
However, carers rated their relatives' improvement in everyday communication as 4.6% higher with the addition of computer therapy than with available speech and language therapy alone.

Benefits attributed to computer therapy were described in previous qualitative interviews with people with aphasia and their carers (Palmer et al 2013).

Most people didn't use their **new words** in **conversation.**



One third of people **did use** their **new words.**



We need to give people with aphasia **more help** to use their **new words** in **daily life.**

Did the computer word finding therapy help people find words that were not specifically used in therapy?

About half of the people with aphasia in all 3 of the groups showed improvement in finding words that were not specifically practised in therapy. **There were no significant differences between the groups in their ability to find words that hadn't been used in therapy.** This suggests that the computer word finding therapy helps improve the ability to find the words used in therapy but that it does not offer additional improvement in word finding more generally in people with aphasia more than 4 months post stroke.

We can therefore assume that people with word finding difficulties more than 4 months after stroke **'get better at saying what they practise saying'**. If this is the case, it is very important that words used in therapy are personalised to make sure the words being learned are useful to the individual person's life.

It is not always easy to find out which words are particularly important to individual people with aphasia and it can be time consuming to prepare pictures for every new word. Therefore the Big CACTUS team identified words that were particularly important to the people with aphasia in this study to help to inform future therapy materials. The word cloud above shows the most popular 100 words.

Further information on what people with aphasia want to be able to say can be found in: Palmer et al, (2017)

People with aphasia get **better** at **saying** what they **practise saying.**

They may **not** get **better** at **saying** things they **didn't practise.**

It is **important** to **practise words** that are **useful.**

Is the computer word finding therapy cost effective?

The computer word finding therapy was **unlikely to be cost effective for all people with word finding difficulties.**

It was more likely to be **cost effective for people with mild and moderate word finding difficulties.**

In order to estimate cost effectiveness, health economists work out how much a new health care treatment costs and how much it changes quality of life. From these two pieces of information they calculate an incremental cost effectiveness ratio (ICER). ICERs can then be used to compare lots of different treatments. A standard questionnaire called the EQ-5D is often used to estimate quality adjusted life years (QALYs) which are used in the calculation.

If patients are unable to complete the EQ-5D themselves someone who knows them well is usually asked to complete it on their behalf. In the Big CACTUS study we added pictures to the EQ-5D to help people with aphasia to fill it in themselves. (Whitehurst et al, 2018) We based the main cost effectiveness result on the picture supported EQ5D.

Group of patients	ICER per QALY gained
Everyone in the study	£42,686
People with mild word finding difficulties	£22,371
People with moderate word finding difficulties	£28,899
People with severe word finding difficulties	Computer therapy more expensive and less impact on quality of life than available SLT
Everyone in the study (using a relative to complete the EQ-5D on the behalf of the person with aphasia)	£28,819

NB: The National Institute of Health and Care Excellence (NICE) use a cost effectiveness threshold of £20-30,000 per QALY gained to help decide whether to offer a new treatment.

Health economists use the term uncertainty to describe how accurate their cost effectiveness estimation is. In this study the uncertainty was quite high because of the variability seen in the results of the quality of life measures.

NB The EQ5D is used as it allows treatments to be compared. However, it does not contain any specific questions about communication.

The **computer therapy** is probably **not good value** for **money** for **everyone** with word finding difficulties.

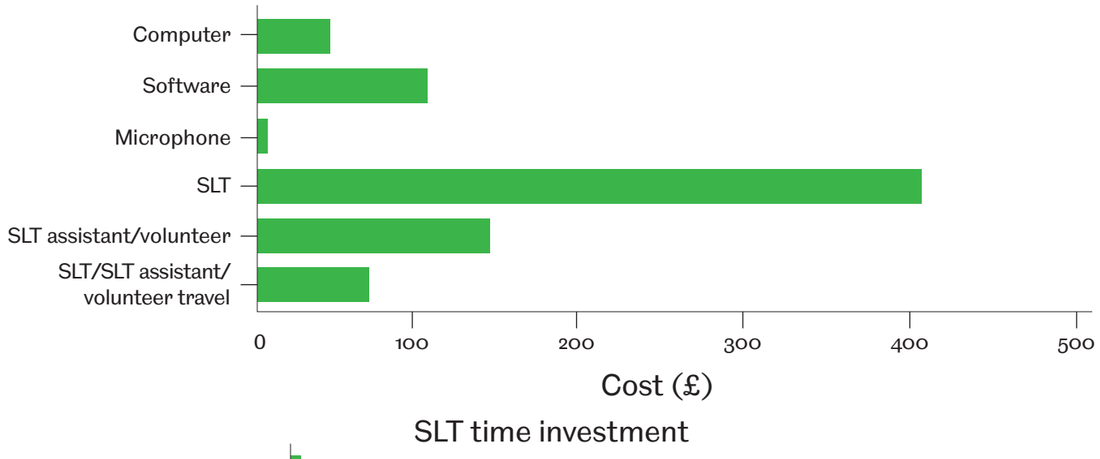
But the **computer therapy may be good value for money** for people with **mild and moderate** word finding difficulties.

Cost of delivering speech and language therapy using the computer approach and comparison with face to face therapy costs.

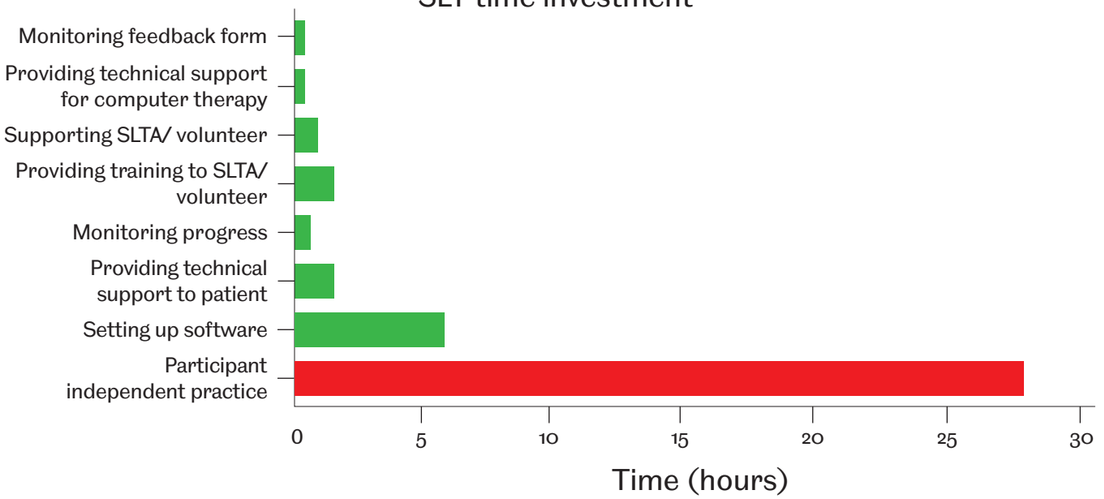
The average cost of the computer therapy approach for word finding was £733 per person with aphasia.

If the same amount of additional therapy time (28 hours) was delivered **face to face** (by mid-grade speech and language therapists) **it would cost twice as much – £1400.**

Breakdown of the costs of the computer approach to the word finding therapy



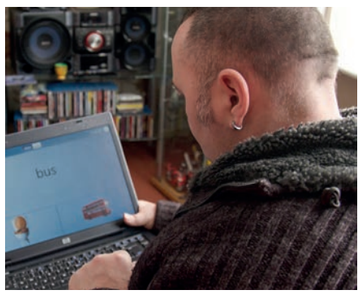
SLT time investment



Although the approach to therapy uses computers for independent practice, some speech and language therapist time was still needed to set up the software to meet the needs of each person with aphasia before it was given to them. This included making sure the words in the therapy exercises were useful. The time spent setting the software up enabled the people with aphasia to do many more hours of word finding practice independently.

The **computer therapy is cheaper** than the same amount of extra **face to face** therapy with a speech and language therapist.

It is **half the cost.**



Conclusions

People with aphasia can have more speech and language therapy with a computer than is often available face to face. It allows them to practise their language on their own.

The computer therapy improves the ability to find words that are important to people with aphasia.

A speech and language therapist is still needed to make sure the computer therapy meets the needs of each person with aphasia. However, it is still half the cost of providing the same number of additional therapy hours face to face on average.

The cost effectiveness of the computer therapy is uncertain, but it is unlikely to be cost effective for all people with word finding difficulties. It is more likely to be cost effective for people with mild and moderate word finding difficulties.

The majority of people with aphasia do not automatically use new words in conversation or everyday communication situations. Therefore, they do not notice improvements in their communication or quality of life. However carers do notice some improvements in their communication.

We need to focus on ways to help people with aphasia to use their new words in useful situations. This may contribute to improving quality of life. This might be achieved by asking volunteers, assistants or family members to spend more time practising the words in real life situations. It might also be achieved by practising finding words in computerised examples of real life situations.

Greater increases in quality of life would also help increase cost effectiveness of the therapy. Although the cost of the approach we used is low, further cost savings might be considered in the future. For example using telehealth (supporting the person with aphasia via the computer from a distance) could reduce travel time of therapists and assistants/volunteers. Assistants/volunteers could add useful words and pictures instead of the speech and language therapist. With time computer therapy options are also likely to cost less.

Computer therapy provides the possibility of more language practice. This can be considered as an important part of a speech and language therapy package to meet the needs of people with aphasia.

Further work

Madeleine Harrison is conducting a PhD funded by the Stroke Association to understand:

- Which parts of the computer therapy approach we used are most important to help people with aphasia improve.
- Characteristics of people with aphasia who do well with the computer therapy approach
- Characteristics of people with aphasia who are motivated to carry out self-managed therapy with a computer

Some of the people with aphasia who took part in Big CACTUS are also having brain scans as part of the Wellcome Trust funded PLORAS study (predicting language outcomes and recovery after stroke). Further information is available here: **www.ucl.ac.uk/ploras**

We hope this might help us to see if different types of brain damage after a stroke make it more or less likely that improvement can occur with the computer word finding therapy.

These studies aim to help us understand who is most likely to benefit from self-managed computer word finding therapy.

Glossary

Aphasia – an impairment of language following brain injury. It can affect speaking, understanding, reading and writing.

Aphasia software – computer programs designed to help people with aphasia to improve their language

Big CACTUS – a research study to assess the Clinical and cost effectiveness of Aphasia Computer Treatment versus Usual Stimulation or attention control long term post stroke (CACTUS)

Carer – a family member or helper who regularly looks after someone

Computerised therapy – speech and language therapy delivered on a computer

Cost effective – good value for money for the amount of benefit

Exclusion criteria – characteristics of people who were excluded from the study

Face to face – the person with aphasia and the speech and language therapist are in the same room

Health economists – people who estimate cost effectiveness

Inclusion criteria – characteristics of people who were included in the study

Incremental cost effectiveness ratio (ICER) – a number used to compare how cost effective different treatments are

Qualitative interview – a conversation between a researcher and a person with aphasia to find out their thoughts about using the computer therapy

Quality adjusted life years (QALY) – a measure of the state of health of a person in which the benefits, in terms of length of life, are adjusted to reflect the quality of life.

Randomised – assigning people in a research study to different groups without taking any similarities or differences between them into account.

Randomised Controlled Trial (RCT) – a study in which a number of similar people are randomly assigned to 2 or more groups to test a specific treatment

Speech and Language Therapists (SLT)s – people who provide speech and language therapy for people with aphasia

Speech and Language Therapy assistants – people who assist with speech and language therapy for people with aphasia

Statisticians – people who carry out statistical calculations

StepByStep © – a computerised therapy program used to practise language skills

Stroke – a sudden brain attack

Volunteer – an unpaid helper

Word finding difficulties – an inability to find the correct word

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