

# Engaging with people who have aphasia

A set of resources for stroke researchers

Delivering research to make patients, and the NHS,  
better

I am delighted to introduce this new resource: 'Engaging with people who have aphasia - a set of resources for stroke researchers.'

The voice of people with aphasia is vital to stroke research. Their involvement is key to its relevance, how it is run, and its reach. It can have a positive effect on their sense of personal wellbeing at a time of great personal challenge. It is often fulfilling for the researchers and health professionals who work with them.

This booklet, which has been developed in partnership with people with aphasia, aims to guide stroke researchers and give them the confidence to be inclusive in the way they work.

It contains a wealth of helpful information as well as ready-to-use materials and links to other sources of advice.

A resource like this does not in itself remove barriers to involvement. However, in the hands of the committed research team that is willing to put its contents into practice I have no doubt it will. They must be supported in this commitment by those around them including people with aphasia and carers.

Making research more inclusive of our diverse communities is one of the challenges of our times. This resource focuses on one particular group of people who have much to give to research. But, given the universality of many of its messages, I hope it will be picked up and used by colleagues in other areas of research as well.

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## Contents

Foreword .....	2
Introduction .....	4
Aphasia and research .....	5
User involvement in developing the resources.....	7
What is aphasia?.....	8
Prepare yourself and the research team .....	8
Cost implications .....	9
Communication skills .....	10
Better conversations with people who have aphasia.....	12
Set the scene .....	13
Help someone to understand .....	13
Help someone to express themselves .....	15
Writing for people with aphasia .....	15
Using images .....	17
Development of the resources .....	18
The images.....	18
The text.....	20
The need for variety .....	20
The templates.....	22
How to use the templates .....	24
How to explain your research.....	24
Checking that the person understood your research information.....	26
Consent.....	27
Meeting invitation or appointment.....	28
Research summary .....	28
Summary of findings .....	29
Make a DVD.....	29
PowerPoint.....	30
Who else can help? .....	30
Table of difficult words .....	31
Conclusion .....	32

We hope this set of resources gives you the information required to implement your own aphasia friendly information. This will help support the recruitment of people with aphasia to research. The following images are available for you to download into your own documents.

.....	32
The stroke story.....	33
What is a stroke.....	33
Finding out what has happened.....	36
Treatment.....	40
Hospital staff and how they help.....	42
Physiotherapist.....	45
Occupational therapist.....	47
Speech and language therapist.....	49
Other hospital staff.....	53
Leaving hospital.....	54
At home.....	56
The effects of the stroke.....	57
Getting on with life.....	61
The research story.....	65
Bibliography.....	91
Appendix.....	91

## Introduction

NIHR Clinical Research Network Stroke recognised that not enough people with aphasia were involved in their research studies. They identified the funding to

engage a stroke and aphasia specialist to develop aphasia resources over for a 6 month project in 2013/14.

This project involved:

- A literature search for relevant evidence
- A mapping exercise to identify existing aphasia resources nationally and internationally
- Engaging with stroke and aphasia researchers to identify their challenges
- Consulting with people with aphasia to identify preferences for resources
- Establishing a user group comprising people with aphasia and carers new to this work and those with experience of user involvement in research
- Working with the user group and with support from a graphics designer to develop new aphasia materials.

These processes informed the development of this resource with the overall aim of equipping researchers to engage more people with aphasia in their research activities.

## **Aphasia and research**

People who have communication difficulties such as aphasia are often excluded from research. There is additionally a marked risk that those who agree to participate do so without a full understanding. Researchers say they feel that they lack the skills or resources to better include people with aphasia. This is understandable as without knowledge, skills and resources it can be hard to engage people with communication difficulties in research conversations, whether these involve spoken or written language. This is challenging for researchers who need to have conversations with people as participants; or as part of the research process as a source of ideas, as consultants, steering group members, user groups or coresearchers. However, it is important that researchers distinguish between people who lack the capacity to consent and those whose competence is masked through the use of traditional methods of obtaining consent.

Stroke researchers' faces particular challenges as one third of people after a stroke have aphasia. People with aphasia are not the only ones who find it difficult to engage in any process which involves standard written or verbal communication.

Other groups include people with dementia, learning difficulties, with English as a second language and those with low general levels of literacy. Any of these people may also be affected by a stroke.

We know that more can be done to facilitate involvement of people with aphasia whilst recognising that some with more marked aphasia may still be unable to participate. Adjustments to researchers' communication styles and the use of appropriate resources can support the research process. Without these necessary changes, this large group of people is potentially excluded. This can damage the quality of the project, the recruitment, and the generalisability of the results.

This resource is designed to assist researchers to be more inclusive and enable patients with aphasia to engage in research. It signposts existing sources of help, gives tips for better communication, and includes a set of phrases and matching images which can assist with writing stroke research information. Finally, there is a set of templates using Adobe software which can be populated with the details of a research project and which will assist in creating accessible documents for all stages of the research process. These include templates for appointment letters and meetings, participant information forms, consent forms and research summary information. The resource images are free for researchers and have been specifically designed by people with aphasia to be realistic and stroke relevant for services in this country. The resources have all been designed with consideration for the ethical requirements for research in the UK.

## **User involvement in developing the resources**

This project has invested heavily in user involvement to ensure that the resources produced are appropriate from the perspective of the end users. The research literature on accessibility has served as a starting point for the user group discussions. The new resources have been developed through a process of facilitated discussion for each aspect in fine detail. The final resources have been double checked by people with aphasia more widely than the user group. This extended process has ensured that the resources meet the needs of those who will use them. However, there is still a need to involve users in your research, not only to assist with the overall project but also to build on the materials in this project and customise for your research.

## What is aphasia?

Aphasia is a complex communication difficulty. Caused by damage to the language centres of the brain, it affects 1/3 people after a stroke, although it can also be caused by other neurological damage such as a tumour or head injury. In individual patterns of type and severity it affects the ability to understand and use both spoken and written language, numbers and gesture.

Aphasia can be difficult to detect. It can be adversely affected by fatigue, emotion, medication, and distracters such as noisy environment. Other factors are an increase in the complexity, quantity, and pace of communication, and after an intense spell of conversation, which, for some people can be quite short. It can cause challenges with planning and organising and can mask ability. It can cause exclusion and isolation; people living with it report frustration and anxiety.

NB: 'Aphasia' is used nationally and internationally as an umbrella term to cover all types and severities of the language processing difficulty. Previous use of 'dysphasia' has not been helpful for people living with it; there is confusion both with the similar sounding 'dysphagia', and there is conflict with the international preference for 'aphasia' which causes difficulty when searching for and sourcing help if there are two different terms in use.

## Prepare yourself and the research team

Engaging people with communication challenges in research has legal and ethical considerations. You need to be familiar with the requirements for your research.

There is a range of information and guidelines related to the Mental Capacity Act, ethics guidance for research, the Disability Discrimination Act and patient and public involvement in research.

<https://www.scie.org.uk/publications/mca/files/mcafactsheet.pdf>

<https://www.hra.nhs.uk/resources/research-legislation-and-governance/questionsand-answers-mental-capacity-act-2005/>

<https://www.scie.org.uk/research/ethics-committee/files/good-practice-guidelines.pdf>

<https://www.hra.nhs.uk/planning-and-improving-research/research-planning/prepare-study-documentation/>

<https://www.nidirect.gov.uk/the-disability-discrimination-act-dda>

INVOLVE supports public and patient involvement in research. They produce a range of guidelines which, may assist your process [www.invo.org.uk](http://www.invo.org.uk)

## Cost implications

Supporting people with aphasia and designing appropriate resources can be time consuming and therefore costly. Adjusting the overall research timescale and costing will ensure that the research better accommodates the needs of people with aphasia. People who do not use English as their primary language are offered adjustments in the form of timing of interaction, support from trained interpreters, and translated literature; people with aphasia require similar consideration.

The INVOLVE website gives assistance with part of this process for costing user involvement in research <https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/calculator/>. The additional expense for involving participants with aphasia is not as easily calculated, however, you may need extra time and money for:

- Staff training in developing communication skills
- Staff training for writing in an appropriate style
- Developing written resources and any images
- Research conversations – participant information, consent, research instructions. These will need extended time, possibly over more than one face to face conversation.
- Feedback process
- The requirement for more face to face supported conversations rather than email, letter or phone
- Extended user group involvement to allow for a slower pace
- Additional facilitators for group conversations or more challenging conversations.

## Communication skills

Communication is an interaction involving at least two people. The success of a conversation is the responsibility of all involved. If someone has a specific communication difficulty such as aphasia they should not automatically be excluded from the research activity; there is much that a researcher can do to provide 'ramps' into the conversation. This is a skill which needs to be developed and practiced; it is often overlooked at a time when there is already much to do. Investing time and finances at the start of the research to learn or refresh appropriate communication skills can pay dividends throughout the whole process. Changing your style for both written and verbal communication may involve a process which, includes training, getting feedback from people with aphasia (who are supported in this process), a period of self-reflection, and practice to establish new skills. Your new skills will be relevant for all parts of your research process.

There are sources of training -

Most stroke or aphasia organisations have information on their websites which will be useful for researchers. There are online training courses and written guidelines e.g. through <https://www.aphasia.ca/health-care-providers/education-training/training-programs-workshops/>

Some stroke or aphasia specific voluntary sector organisations provide training courses e.g. The Stroke Association, Speakeasy, Connect. Contact details are on [www.aphasiaalliance.org](http://www.aphasiaalliance.org) Some of these involve people with aphasia as co-trainers who give feedback about a person's individual communication style; researchers positively evaluated this style of training.

As part of your research you will need user involvement of people with aphasia. Reach out to involve people whose aphasia impacts strongly and especially on reading and writing. This can be challenging. There are voluntary organisations that may be able to assist either in supporting the research itself or by facilitating access to people with aphasia [www.aphasiaalliance.org](http://www.aphasiaalliance.org)

In addition to the information for people with aphasia you can learn from guidelines designed for working with people who have different communication challenges.

There are resources to help such as CHANGE [www.changepeople.co.uk](http://www.changepeople.co.uk) aimed at people with learning difficulties and

<http://www.scie.org.uk/publications/briefings/briefing03/> for people with dementia.

## Better conversations with people who have aphasia

The guidance in the next few pages are designed to remind people of what needs to be done; they are not intended to replace more in-depth training.

With either verbal or written communication first consider the tone. Researchers and medical professionals often talk in a way which is both inaccessible and off putting for the general public. Ensure that communication is respectful, clear and open, and engages in a way which, marks those in the conversation as equal and competent partners.

A conversation which, happens at a time with consideration for the person with aphasia and not just convenient for the research routine is far more likely to be successful. Is there a good time of the day when someone is less tired? Do medicines affect communication at certain times of the day? Should the conversation happen across more than one meeting?

Prepare yourself in advance of any conversations. Have you got the right skills? Have you got the right resources ready? Do you need any additional information before the conversation starts?

People with aphasia tire more easily, as it can be an effort for them to join in the conversations. Is there anything you can do to reduce the load on your conversation? For example, have you already got the relevant contact details or medical summary on file, do you really need them to repeat it?

Can you find out more about the person which might help the conversation? Has a speech and language therapist been involved, maybe they could help to give an idea of how to provide support? Is there someone else such as a friend or carer who can give you tips?

There are screening tools which might help indicate whether a person has aphasia; they give a broad indication of the type and level of difficulty e.g. The FAST (Frenchay Aphasia Screening Test) <http://www.stass.co.uk/publications/fast>

The Consent Screening Tool was specifically developed to assist researches to identify the appropriate type of resources for the consent process.

[www.informahealthcare.com/doi/abs/10.3109/17549507.2013.795999](http://www.informahealthcare.com/doi/abs/10.3109/17549507.2013.795999)

## Set the scene

- Reduce or eliminate background noise as people communicate poorly against even low level noise such as conversations in another part of the room, television at a distance and tapping on keyboards
- Cut out any distractions. If possible have conversations in a room with a closed door
- Arrange the seating so that the person with aphasia faces towards a blank wall, this reduces visual distracters
- Make sure the person has any required glasses or working hearing aids
- Make sure you can see each other's' faces to look for extra clues
- Have any resources for the conversation to hand and within easy reach on a shared table space at the right height to allow for writing. At the very least these resources should include the research information and pen and paper
- Time pressures exacerbate aphasia. Allow plenty of time and be explicit that this is OK. Plan for time for the researcher to explain information clearly at an appropriate pace, time to repeat as necessary, time to process the information and time to think about and give the response. Most people without communication challenges are very poor at allowing enough time before they feel the need to fill a silence.

## Help someone to understand

- Speak clearly and slightly more slowly, but keep normal intonation
- Keep sentences simple – one idea for each sentence
- Keep sentences short. Plain English sentences should have around 15 words; a very clear aphasia accessible sentence will have around 5 words.
- Have a slight pause between each sentence
- Give enough background to set the scene for the conversation, but leave out unnecessary information
- Make it clear if you are changing topic - we have just talked about [point to picture] - pause - and now we are going to talk about [point to picture]
- Don't use abbreviations

- Don't use acronyms
- Use a personal style; 'you' and 'we' reach out to the listener or reader more strongly
- Be prepared to repeat your information and rephrase
- Use active tense, passive is harder - 'the doctor will give you information' is better than 'you will get information from your doctor'
- Use facial expressions, body language and natural gesture as you are speaking
- Use the pen and paper to write down key words for the person to read and refer to as the conversation develops. Don't write whole sentences
- Use line drawings to support the meaning. These diagrams do not need to be complex or highly artistic; they are to give the idea of the key points in the conversation
- Summarise the conversation regularly, the words and drawings will help with this. You can then write down any ideas or decisions made during the conversation
- Choose simple words that are commonly used by the general public
- Don't use jargon - it may be hard for you to identify this, you may not realise what other people don't understand. Ask your user group to help. The user group for this project identified some words they find difficult, they are included in the tables on page 29.
- Refer to your work as 'research' each and every time
- Use the same words for the same thing each time doctor/GP
- Don't refer to the research by its abbreviated acronym – aphasia makes it hard to learn new words and the participant will never have heard it before
- Avoid nominalisations - these are nouns formed from verbs e.g. completion, randomisation. They sound abstract and impersonal
- Don't use strings of nouns e.g. patient satisfaction feedback form.

## Help someone to express themselves

- Encourage and respond to any way of communicating – speech, facial expression, pointing, body language, intonation, tone of voice, drawing, writing
- Encourage writing of letters or key words if possible
- Encourage pointing to images or research materials to get their message across. Have relevant images prepared and to hand
- Use your drawings and the words you have written as part of the communication. This can be useful in many ways; the person may point to them to show preferences, cover them up to indicate something negative, look and nod vigorously to express strength of feeling
- Ask questions. Are you telling me about something that happens in the hospital? Are you telling me about something that happens in the doctor's surgery? Use broad questions first then ask more questions to narrow down the options. Only ask one question at once. Questions that require a yes or no response are easier
- Be aware that some people confuse pairs of words; in particular they may mix up yes and no. This can be difficult when asking questions. Double check any understanding you get from this sort of response, see if thumbs up/down is helpful, come back to it later and ask again, does the non-verbal communication 'say' something different from the spoken word
- Regularly repeat back what you think you have understood. Encourage the person to confirm that you have understood all or part of their conversation - Did you mean? Have I got this right?
- Alphabet charts or electronic communication aids are difficult for many people with aphasia. If the clarity of the speech is the only issue and there are no problems with understanding then these may help
- There may be some other resources which can help depending on your particular topic of conversation – local maps, pictures of activities, photographs of family
- Don't pretend to understand, admit if you are struggling. You may agree to come back to a discussion and try again later (but don't forget to do this).

## Writing for people with aphasia

The same considerations for choice of vocabulary apply to both spoken and written language but giving additional consideration to layout and the overall look of the document can transform the accessibility. Even the best content can be inaccessible if the layout is wrong.

- Only use capitals at the start of a sentence and names
- Use at least 14 font, preferably 16 or 18
- Use a clear font such as Arial, Verdana or Calibri
- Don't use italics
- Don't underline, it affects the shape of the word
- Include plenty of white space on a document. Don't be tempted to squash things up to save on paper or ink
- Draw attention to key words using **bold** and **increased font size** (Control + B, and control, shift + >)
- Put a double space between words.
- Make the line spacing 1.5
- Justify text to the left
- Don't split words across more than one line
- Don't split sentences across more than one page
- Use colour to help with emphasis, or to help navigation in a document e.g. with topics
- Questions or general headings help guide the reader
- Use a new line for each sentence
- Bullet points help
- Cluster information and images by using text boxes as cells or outside borders.
- Use only a few cells per page; one per page will help some people
- Cut out any additional words or unnecessary detail
- Don't use headers and footers, they are very distracting
- If you get the layout right you don't need punctuation; it can distract and alter the shape of a word
- Keep your style the same for each and every document you use, this helps to identify it as part of your research

- Codes and research information about data storage is inaccessible. When these are tucked at the top or bottom of a document they affect both the accessibility and the tone, research can feel like a secret world.

For more information about writing in a clear and accessible style

<http://www.stroke.org.uk/sites/default/files/Accessible%20Information%20Guidelines.pdf.pdf> - Aphasia Information Guidelines – making aphasia information accessible

Including People with Communication Disability in Stroke Research and Consultation

[www.ukconnect.org](http://www.ukconnect.org) [www.plainenglish.co.uk](http://www.plainenglish.co.uk)

<http://www.changepeople.org/free-resources> and <http://www.changepeople.org/buyour-resources>

[www.mencap.org.uk](http://www.mencap.org.uk) Make it clear [www.talkbank.org](http://www.talkbank.org)

Aphasia bank [www.communicationforumscotland.org.uk](http://www.communicationforumscotland.org.uk)

[www.scie.org.uk/publications](http://www.scie.org.uk/publications) making information easier

Research is often written in a way which, is inaccessible to the general public and uses a style and vocabulary that requires a high level of language processing. There are ways to check your documents readability on your computer. Various programmes can help indicate if your language level is too high; although there is variability between these and they focus on different aspects of writing to reach their score. The Flesch-Kincaid Readability check is already on Microsoft. For 2010 Word follow these steps:

- File - options- proofing- show readability statistics
- Spell check the document as normal
- A box with readability statistics will appear
- The grade level should be 6 or below.

## Using images

A carefully chosen image can support increased understanding for many people with aphasia. There are often strong negative opinions amongst researchers and ethics committees about images as they are often seen as childish, patronising or unprofessional. However, people with aphasia know that they help considerably as a vital component of the adjustments they need. It appears that it is people without language challenges who don't like them. This dislike of images has possibly arisen through the overuse of those easily available from the internet or clip art or through

the use of home drawn pictures. Anything which is aimed at children, is overly simplistic, posed to look pretty, or taken from a country or culture which is inappropriate for the research is not ideal. An image should assist with understanding; it is not there to make a document look more attractive.

The researchers consulted through this project reported variations in response from ethics committees to their use of images and adapted text for people with aphasia. One researcher reported that the same research documents submitted to different committees were celebrated by one as a beacon of good practice, whilst being rejected as 'inappropriate' by another. Use the background information in this resource to help ethics committees understand the need for this approach to presenting research information.

## **Development of the resources**

### **The images**

The mapping process for this project confirmed that some researchers do use images to support understanding. However, the images used are highly variable in quality. Researchers have not had easy access to free appropriate images.

This project presented a unique opportunity to consult and work with people with aphasia, to design a new set of images from scratch, rather than from expressing preferences about existing images. These images are free for researchers.

The first stage of the process involved consultation to identify a preferred overall style for the image collection, and to identify key aspects for a useful and informative image. Two hundred and sixty five people with aphasia contributed and the results confirmed that they value and need images to help their understanding. Given an absolute free choice they prefer well drawn and realistic diagrams. Photographs are often clear but diagrams that look like photographs are even better, people in such images are easier to relate to as being "like me but not meant to be me"; this reduces the need to have images for different ethnic, gender and age groups. In

addition, photographs can be too intrusive especially for some medical procedures, and diagrams can be better at showing information about internal parts of the body.

There are some key pointers for using images:

- Exclude background which distracts, any background should only be included if it provides additional information
- Make sure the image and words match
- Place the image on the paper so the reader sees it first – either to the left of the words or above
- Colour helps
- If possible use the same style of images throughout all documents
- Use adult and stroke appropriate images.

Taking this information forward; the second stage established a process to develop new images in the chosen style. The process required the project manager and user group to take the following steps:

- Identify 200 key images required for stroke research
- Consider the essential elements for each image. Existing internet images and aphasia resources helped with widening choice and making decisions
- Pose the images for photographs if possible and with assistance from healthcare professionals as appropriate
- View and consider each photograph, re-posing as necessary
- Discuss the requirements for each image with the graphics designer involved in the project
- Task the graphic designer to draw the required image using appropriate software
- Scrutinise and adjust each proposed image

**Each image adhered to agreed principles such as:**

- All people portrayed as having a stroke would wear an item of clothing in purple (this was chosen to be close to the Stroke Association's corporate theme) •  
Researchers, and in particular those in the consent images, would wear orange
- Clothing would be in the style as worn by UK healthcare professionals.

This attention to detail assists understanding of the concept portrayed even with limited understanding of any accompanying words. The painstaking process of feedback and alterations has ensured the best possible design.

## **The text**

The process to support understanding involves the use of both images and appropriate text. The user group developed accessible text about common aspects of stroke and research. They considered each part of the text to give the right message even if only key words are understood. They considered general layout and quantity of the information presented. The text is written in a detached style to describe the stroke process; this makes it usable for different types of research. Research about personal experiences of stroke would require different phrasing from one looking at service redesign. If relevant the text should be converted to a personal tone - your stroke, you had treatment. An active personal style reaches out to the reader more strongly.

The images and accompanying text have been clustered into the story of what happens after a stroke; this assists you to locate the right images and text for your research pages 30-57. The scale of this project has only allowed for the development of a small selection of common phrases for presenting research information; however they are included pages 58 onwards.

## **The need for variety**

The images, the text and the layout collectively and incrementally contribute towards the aphasia accessible style. However, people with aphasia are not an homogenous group and they need information presented in a way suitable for their individual difficulties [3]. Some people with aphasia which, does not impact as strongly on their understanding of writing, may prefer information in plain English. Use the accessible style in these resources to develop a plain English version which may have slightly more detail and adjustment to aspects such as sentence length. Either of these versions may be useful for other people who do not have aphasia. People with learning difficulties, dementia or low levels of reading comprehension may find it easier to understand the aphasia accessible versions. A carer who contributed to this project commented "I would have preferred the information written like this

[aphasia accessible consent form]. Easier to understand. There is so much to think about after a stroke you want things as simple as possible”.

## The templates

The document templates included with this resource make it easy for researchers to write information for people with aphasia. They have been shaped by people who will use it – people with aphasia, researchers and those involved with the ethics process. They are designed to be an essential element in the research process, but they are not the whole solution, researchers will still need to use other communication support strategies for engaging with people who have aphasia.

There are templates for explaining the research, for taking consent, for giving research information, letters and invitations to meeting or appointments, research summary and summary of findings. In addition there is a check to help decide if it is appropriate to proceed with taking consent to participate in the research. There is variation in the detail required for populating the templates. The consent form only requires selection from a menu of options, whilst the information about the research requires the clustering your own information using the headings in the template; this is necessary as your research project will have its own unique focus. However, your information can still draw upon the resource in the stroke and research stories.

The user group wanted researchers to understand why they need the changes and why it is necessary to use the templates as designed by them.

- None of the user group involved in this project used the research name for any research with which they had been involved. All preferred a simple image e.g. a toilet for a continence study. This image is not to explain the research but to act as a visual identifier. Combine this with a colour and design theme on each and every document.
- Too many logos at the top make a document instantly difficult for them “too much, too much, makes me want to give up already”. Additional logos should go at the end.
- Titles for documents such as ‘Participant Information Forms’ are generally meaningless for people outside the research team. Researchers use them to assist with administration. If you design your documents with the reader in mind you would not use these headings.

- Footers and headers can make a document inaccessible for people with aphasia. They can be very confusing; not only are they visually distracting but people can waste a lot of energy trying to understand them.

## How to use the templates

- Select an image as something to identify your research document visually recognisable. This will go in the top left corner of the documents as the first thing that people see
- Insert your logos; the main logo goes at the top of the first page, additional logos will go at the end
- Summarise the project in a very short and very simple sentence; don't go into specifics. E.g.
  - Testing a new treatment for stroke
  - Help with walking after a stroke
  - What you think about help after a stroke
- Your research acronym (if you have one) means nothing to the general public. Put this after the simple explanation. Use colour to explain e.g. **ICONS** – **I**dentifying **C**ontinence **O**ption**S** after **S**troke
- Add the name and title of the main researcher, with a good quality head shot photograph
- Insert the contact details, phone number (direct line) address (written as though it is on an envelope) and the email address.

When you have completed steps 1-3 you will have the details which can be inserted into the template and which will then populate all your research documents.

You are now ready to consider the specifics for each research document.

## How to explain your research

Your research process may need to start with a clear and concise explanation about a stroke and its effects. Many people after their stroke struggle to understand or remember what has happened to them. You may need to explain all or many of the aspects of stroke, or you may be able just to give a general outline followed by details on the aspect of stroke covered by your research. Keep it as brief as possible whilst setting information in context.

Use the resources to copy and paste relevant sections of text. Keep the layout and spacing of each sentence the same, even the slightest change could affect the accessibility. However, the spacing of your document will need to be different, use only 3 or 4 sentences and images for each printed A4 page; some people may need only one per page. To select the images you require you will need to go directly to the image file to get the best resolution, 'copy' and 'paste' from the word document will affect the quality. The images vary in size; ensure that your image is large enough to show detail, this will be larger than the examples used in the stroke and research sections.

The images are labelled with the most obvious option for their use; however, be creative. For example:

- The image for a focus group could equally represent a researcher giving instructions or explaining to a group what is happening in treatment
- Use a cross or tick at the side of an image to give an opposite meaning.
- Use one tick by an image to suggest good, use two ticks to suggest very good.

The scope of this project has allowed for 200 images and phrases. Whilst this gives a good range your research may need additional specific resources. Any further images required should be as close as possible to the design style of those in the library. Photographs can be an easier and cheaper option than employing a graphics designer. However, make sure they are high resolution, taken in good lighting, close up to the action, and with clear background. All should show the activity rather than the person posing or an object e.g. for research about treatment for climbing stairs show a physiotherapist actually giving the treatment rather than the steps alone or a smiling physio looking out of the page. Obviously make sure that you have consent for any photographs. There are other sources of images which may assist, not all of them are free:

- [www.aphasiafriendly.co.uk](http://www.aphasiafriendly.co.uk)
- Pictographic Communication Resource [www.aphasia.ca](http://www.aphasia.ca)
- Clip art (Caution! Many of these images are not appropriate).
- Picture Banks produced by CHANGE - [www.changepeople.co.uk](http://www.changepeople.co.uk)
- Signpost resources - [www.communicationforumscotland.org.uk](http://www.communicationforumscotland.org.uk)
- Google images - Most are subject to copyright regulations; they are generally designed to be decorative, few are appropriate for giving accurate information.

Some internet sites allow free use of images e.g. [www.freestock.com](http://www.freestock.com) and [www.stockfreeimages.com](http://www.stockfreeimages.com)

Creative use of these resources can ensure that you maximise understanding. Try giving an overview of the research using a very simplified version perhaps presented as a power point presentation with sound or embedded media clips. Once the key aspects have been understood then introduce a version with slightly more detail. Some people may prefer this to be done the opposite way with the very simple version last and acting as a summary to check that key points have been understood.

The information giving and consent should be regarded as a process rather than as a one off event particularly where it involves people who communicate differently. It may take time for someone to consider the research information; they may also want to discuss it with their family. You may need to leave the information with the patient and return at a later date, or break down the information into small steps. This may take considerably longer; you may need to set up a process to allow for re-visiting the research information, on several occasions, using different formats, and maybe involving other people who have skills to assist with the communication. Might it be worth purchasing a DVD player so that a DVD can be re-viewed in a person's own time? This might be appropriate if you are recruiting from a stroke ward where the equipment can be stored.

### **Checking that the person understood your research information**

For something as important as consent to participate in a research study it is essential that a person really understands what is involved. The consent check in the templates section of this resource suggests ways to help you to decide. Explain to the person that this is not a test to catch people out but that is part of the research. Note that there are no absolute right and wrong answers to some questions on this form, the responses depend on the nature of your research. You may also use the consent resource in the appendix [Thanks to R Palmer, University of Sheffield for this document].

If there is evidence that there are some misconceptions about the research then you can start the process again. You may want to vary the process from the first time you tried. Here are some suggestions for how to try again:

- Use a different format for the information
- Use more than one format
- Try at a different time of day when the person may be less tired
- Try in several stages if the research information is quite complex
- Get help from someone else
- Consider whether the person lacks the capacity to consent
- Consider obtaining assent from a carer if appropriate.

## Consent

If you are confident that the person has understood the research and implications for taking part you can progress to the consent process.

Pages one and two in the consent template are all that you need for a standard consent form for many research projects. If there is other information you need to include, select them from the drop down menu. There is also a blank section for anything not included. It is unlikely that you will need this as the consent form provided here is enough to satisfy the requirements for ethics approval. If you do need this, make sure that you chose an image and wording that meet the guidelines in this document.

You may note that the sentence length and amount of information presented is greater than that suggested as ideal for people with aphasia. This was done to ensure that the process complies with ethics requirements. The user group for this project recognised that the ethics process requires precise wording which is difficult in very short sentences. They debated such aspects as the difference for them between 'understand' and 'know' (the former being more relevant for new information whereas the latter had connections with existing knowledge). This section may appear less accessible. However, the group felt that the resources were appropriate as the consent forms are highly repetitive and contain information already presented in a shorter format in the research information.

## Meeting invitation or appointment

This document template contains both menus for selection from a drop down menu, and space for insertion of specific details. It can be easy to forget that even such instructions as how to find a building need to be aphasia accessible. Standard Hospital and University maps are often inaccessible, give instructions such as:

Go to the community hall It  
is opposite the park  
It has a blue door It  
has no steps.

Write instructions for what to do on arrival. Include a photo of the receptionist at the desk

Go into the building  
Sarah will be at the reception  
She will be waiting for you  
Give her this letter  
She knows about aphasia She  
will help your communication She  
will take you to the meeting.

## Research summary

People with aphasia can find it hard to remember. It is helpful to give a summary of the key points and the contact details. Put this information onto one page only, laminate if possible, and suggest they store it safely, maybe attached to the back of a cupboard door.

## Summary of findings

Using the template, summarise the key points from any research. Keep it simple – what did we want to know? What did we find? What next?

There are other resources for which we don't have templates e.g. test feedback, website information, newsletters about the research, signage for meetings, expense claims or appointment cards. Apply the same rules as used in the templates to make them part of your set. If you use different formats pay attention to details such as ensuring that the layout is exactly the same, e.g. written lines break at the same place in each version.

As part of this project people with visual difficulties were consulted about the ease of use of the templates; they confirmed that the templates are acceptable from their perspective.

There are suggestions below on alternative formats and special considerations for each.

## Make a DVD

A DVD can be a great source of help. You can show exactly what will happen, acted by the researchers if possible, and filmed in the actual locations. Use narrative with the same phrases as the written research information. However, keep the DVD short; aim for no more than 5 minutes. Speak clearly in an unhurried manner using simple language and vocabulary, preferably the same as in the written research documents.

## PowerPoint

This software allows you to vary the presentation of your information. It can assist you to:

- Present small amounts of information at once using a separate slide for each chunk. Print out each slide on a separate page. Some people find it much easier to see only one image and one sentence at once
- Record your own narration using the exact words on the screen, there are instructions within Microsoft help for how to do this easily. However, the sound quality is not always the best done this way even with a good quality mic. Consider using speakers in a lap top to enhance the sound
- Embed media files into PowerPoint; film short clips for sections of the research information
- Make a diagram of your research. See the image about a randomised controlled trial for an example.

## Who else can help?

There are aphasia and aphasia research communities nationally and internationally. Contact with them may assist in recruitment, in sharing information which may support both your research and future research for people with stroke and aphasia. Some of these are listed below:

[www.crregistry.org.au](http://www.crregistry.org.au) Communication research registry

[www.britishaphasiologysociety.org.uk](http://www.britishaphasiologysociety.org.uk) British Aphasiology Society

[www.aphasiatrials.org](http://www.aphasiatrials.org) Collaboration of Aphasia Triallists

[www.aphasia-international.com](http://www.aphasia-international.com) [www.aphasia.org](http://www.aphasia.org) [www.asha.org](http://www.asha.org)

[www.aphasia.ca](http://www.aphasia.ca) [www.aphasia.org.nz](http://www.aphasia.org.nz) [www.aphasia.org.au](http://www.aphasia.org.au)

[www.aphasia.asn.au](http://www.aphasia.asn.au)

## Table of difficult words

The words in the tables below were identified by the project user group as being difficult to understand. Do you use any in your writing or when you speak? Use synonyms or check for alternatives to some of them and for other complex word.

<https://www.plainenglish.co.uk/useful-links.html>

### Research terms

Trial	Randomise	Efficacy
Pilot	Intervention	Case study
Tools	Measures	Study
Outcome	Feasibility	Multicentre
Strategies	Evaluate	Placebo
Screen	Baseline	Double blind
Novel	Efficacy	Multiple
Data	Quantitative	Qualitative
Statistics	Control	Domain

### Medical words

Diagnosis	Prognosis	Discharge
Pathway	Multi-disciplinary team	Procedure

Deficit	Impairment	Acute / Sub-acute
Regime	Primary care	Admission
Pre appointment screening	Symptoms	Local application
Biopsy	Impairment	Observation
Screening	Outcomes	Predictors
Care plan	Adhere	Comply

## Conclusion

We hope this set of resources gives you the information required to implement your own aphasia friendly information. This will help support the recruitment of people with aphasia to research. The following images are available for you to download into your own documents.

## The stroke story

### What is a stroke



The **brain** controls **everything we do**

**movement**

**emotions**

**communication**

**thinking**

The **brain** needs **blood**

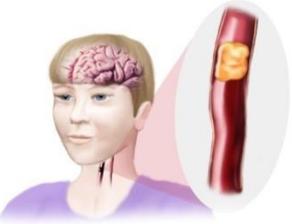
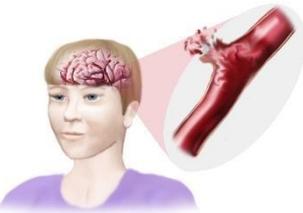
**Blood** keeps the **brain** working

The **blood supply** can **stop**

Then the brain is **damaged**

This can happen **suddenly**

This is called **a stroke**

	<p>A stroke can happen in <b>two ways</b></p> <p><b>Arteries</b> carry <b>blood to</b> the <b>brain</b></p> <p>A <b>blood clot</b> (thrombus) can <b>block</b> an artery</p> <p>Then <b>no blood</b> gets <b>to the brain</b></p> <p>This <b>damages</b> the brain part that the artery supplies</p> <p>This is called an <b>ischemic stroke</b></p>
	<p>The <b>walls</b> of a blood vessel may be <b>weak</b></p> <p>They can <b>burst</b></p> <p>Then the <b>blood spreads</b> into the brain</p> <p>This <b>damages</b> the brain</p> <p>This is called a <b>brain haemorrhage</b></p>
	<p>Each brain part <b>controls different things</b></p> <p>The <b>effects</b> of a stroke <b>are different</b></p> <p>This depends on the <b>area damaged</b></p>

	<p>The <b>left side</b> of the brain controls the <b>right side</b> of the body</p> <p>The <b>right side</b> of the brain controls the <b>left side</b> of the body</p>
	<p>After a stroke people <b>go to hospital</b></p> <p>They usually go <b>in an ambulance</b></p>
	<p>The <b>staff find out</b> about any <b>difficulties</b></p>
	<p>They give a <b>brain scan</b></p> <p>This shows <b>why</b> the <b>stroke happened</b></p> <p>Was it caused by a <b>bleed</b> in the brain?</p> <p>Was it caused by a <b>clot</b>?</p>



If it is a **clot** **Thrombolysis** may help

This is **an injection**

It may **break up the clot**

The **blood** may **flow freely again**

Thrombolysis has to happen in the first **4**  
**1/2 hours**

**Not everyone** can have thrombolysis

**The doctor will decide**



Hospitals have a **stroke ward**

The **staff are experts** in stroke

People go there **as soon as possible**

**Finding out what has happened**



The **stroke staff** are a **team**

sometimes called the **multidisciplinary team**



They **watch** for **any change**

They give **care and help**

They **ask questions** and do **tests**



They find out about **problems**

They decide if **further tests** are needed



**The tests** will look at

Movement of the **arms and legs**



**numbness**



**balance**



**confusion**



**headache**



**communication**

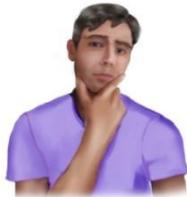
**bladder and bowel control**



**eating and drinking**



**thinking**

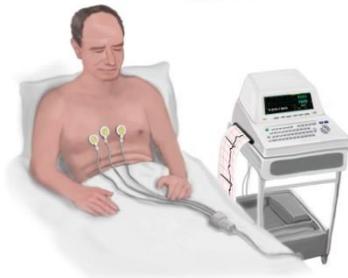


**eyesight**



**pain**





The staff may need to do **medical tests**

These give **more information**

They may need

**blood tests**

**urine tests**

**ECG (Electrocardiogram)**

**blood pressure** checks

**carotid ultrasound**

**X Ray**



## Scan



The staff also **ask questions**



Sometimes **telemedicine** is used

This uses **technology**

It gets **help** from **specialists**

The **specialists** are **not in** the **hospital**



For some people the **signs of a stroke go away** within 1 day (24 hours)

This is called a **Transient Ischemic Attack** or **TIA**

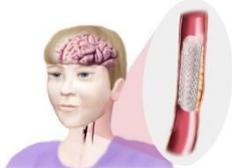


People with a TIA still need to have **regular checks** by their doctor



They may need to have **medicine**

## Treatment

    	<p><b>Medicine</b> may help</p> <p><b>syrup</b></p> <p><b>tablets</b></p> <p><b>injections</b></p> <p><b>suppository</b></p> <p><b>oxygen</b></p>
 	<p>Sometimes a <b>surgeon</b> will <b>operate</b></p> <p>A <b>stent</b> may help some people</p> <p>A stent is a <b>small mesh tube</b></p> <p>It goes <b>inside</b> narrow or weak <b>arteries</b></p> <p>It helps <b>keep</b> the <b>arteries open</b></p>
	<p>This <b>lets</b> the <b>blood flow through</b></p>

## Hospital staff and how they help

 	<p>A <b>stroke consultant</b> makes the <b>medical decisions</b></p> <p>They <b>manage the care</b> in hospital</p> <p>A <b>stroke nurse</b> gives <b>medical care</b></p> <p>They <b>watch for</b> any <b>change</b></p> <p>This is called <b>monitoring</b></p>
  	<p><b>Rehabilitation</b> is <b>help to get better</b></p> <p>It is also called <b>therapy</b></p> <p>There are <b>therapists</b> on the stroke ward</p> <p>They are <b>experts</b> in <b>stroke</b></p> <p>People may <b>not need help from all</b> therapists</p>
	<p>The therapists do <b>assessments</b></p> <p><b>They find out more</b> about any difficulties</p>



They **plan** for **therapy**



They **talk to** any **family**

They tell them about the **therapy**



They **teach** how to **help**



The therapy **plan** may have **exercises**

These should be **repeated often**



Therapists use **equipment** in **therapy**



They may give **equipment to use** all the time



**Therapy** should happen **5 times a week**



It should last **45 minutes each time**



Some people find this **too tiring**

They will do **as much as they can**



## Physiotherapist



A **physiotherapist** checks **movement**

They are sometimes called a **physio**

They check **arms and legs**

They check **coordination**

They check if **muscles are weak**

They check **balance**

They check **walking**

They may **use equipment**

such as an **exercise bike**

or a **treadmill**

They may **give equipment**

They may give a **foot splint**

This **helps with walking**

**Functional Electrical Stimulation (FES)**

This is a small **electric shock**

**The shock** is given to the **nerves**

This **helps movement** of **muscles**



Physiotherapy is sometimes in a **swimming pool**

## Occupational therapist



An **Occupational Therapist** helps with activities

They are sometimes called an **OT**

They help people be **independent** if possible

They help people with **everyday activities**

After stroke it can be **hard** to

**make drinks and meals**



**get out of bed**



keep **clean and tidy**



clean the **mouth** and **teeth**



**get dressed**



look after **the house**

It may be **hard to do** the same **hobbies**



An occupational therapist may give **equipment to help**



An occupational therapist helps with **relearning skills**



## Speech and language therapist



A **speech and language therapist** helps **communication**



Stroke can affect **communication**

It can be hard to

**speak clearly**

**find the right words**

put ideas into **sentences**



**understand** other people



**read**



**write**



use **numbers and money**

A speech and language therapist may give **exercises**



They may teach **different ways of communicating**

They may use **equipment**

They help **family** or **carers** to **communicate**



They may arrange **conversations**

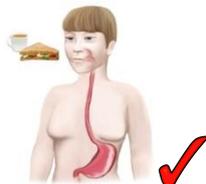
**These will be with people trained** to help



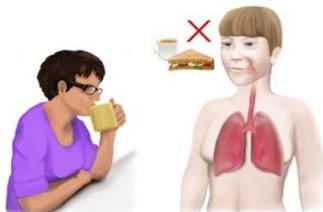
A **speech and language therapist**

Helps with **eating** and **drinking**

They check for **difficulty swallowing**



**Food** and **drink** should go **into the stomach**



After a **stroke** sometimes the **swallow**  
does **not work**

**Food** might go **into the lungs**

**Drink** might go **into the lungs**

Some food and drink is **easier**



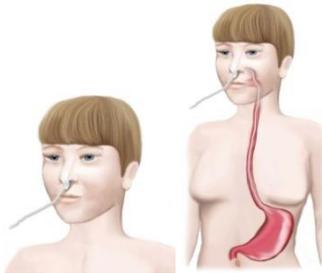
Some people **cannot eat** or **drink**

They may get food **through a tube**

This goes **through the nose**

It goes **into the stomach**

It is called a **NasoGastric Tube NG tube**



They may get food directly **into the stomach**

This is called **Percutaneous Endoscopic Gastrostomy PEG**



## Other hospital staff



**Rehabilitation assistants** help **practice therapy**



A **dietitian** helps people get the right **food**  
This helps them **keep healthy**



A **psychologist** helps with **emotions**

A **psychologist** helps with **thinking**



A **social worker** organises **help from social services**

The help is for **after hospital**



A **pharmacist** helps with **medicines**



An **audiologist** helps with **hearing**



A **podiatrist** helps with **feet**



An **optometrist** helps with **eyesight**



## Leaving hospital



At first **rehabilitation** happens **in hospital**



The **stroke team plan** for **leaving hospital**



The **rehabilitation team** also **plan**

**They plan** for **therapy after hospital**



Any **family or carers** will **help plan**



The stroke team **give** patients the **plan**

The **plan** covers **lots of things**



It may include

**how to claim benefits**



information about **housing**



There is **support and therapy after hospital**

This happens **wherever people live**

There are **different ways of organising** this

Some areas have a **team of specialist stroke therapists**

They are called the **Community Stroke Team**



Some hospitals have an **Early Supported Discharge Team**

Some people can **move** easily **from a chair to a bed**



They **can leave hospital** quite **soon**

These people get **support** and **therapy at home** instead



**Family may help** at home

The **therapists** will **train them**

Stroke can make it hard to **live in the same way**

**Staff** will **check** the **home**

They check it is **safe**

They check it is **suitable**



They may **take people to visit** their home

   	<p><b>Special equipment</b> might <b>help</b></p> <p>This will be <b>ready</b> for going home</p> <p>The staff <b>explain about medicine</b> for going home</p> <p>The <b>hospital</b> staff <b>share information about your stroke</b></p> <p><b>They tell</b> the <b>doctor (GP)</b></p> <p>They <b>tell</b> the <b>community stroke team</b></p>
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## At home

 	<p><b>Therapists visit</b> at home</p> <p>They visit <b>within 3 days of leaving hospital</b></p> <p>They <b>plan</b> the <b>support</b></p> <p>They <b>plan</b> the <b>therapy</b></p> <p>They ask about any <b>changes</b></p> <p>They ask about any <b>new difficulties</b></p>
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The therapists say who to **contact** for **help**

They give a **name**

They give a **telephone number**

There are people who give **support**

They **help people manage** at home

This is their **job**

They are sometimes called **paid carers**

## The effects of the stroke



Every stroke is **different**



**Some people make a good recovery**



Some people still have difficulties



Some people have difficulty with **eyesight**

They may have **double vision**



They may **see half** of what they look at



Some people have **epilepsy**



Some people have **pain**



Many people have **shoulder pain** after a stroke



Staff give **advice**

They tell **how to prevent** this



They will say how to **reduce the pain**

There is **medicine** that **can help**



Some people feel **tingling or numbness**



Some people are **very tired**



Some people **can't remember** things



Some people **can't concentrate**



Some people have **no confidence**





Other people **still** have **confidence**

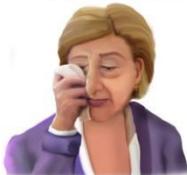
Some people have no **motivation**



A stroke can affect **emotions**



Some people are **happy**



Some people are **angry**



Some people are **depressed**



Some people are **anxious or frightened**

Some people are **frustrated**



Some people **change between emotions**

Stroke can **affect social life**

Some people feel **lonely** and **left out**



It may be **difficult** to go **out and about**

or meet **friends**



**Stroke affects carers** and **families**



**Carers need help** too

**Getting on with life**



The **stroke team** help to **set goals**



**Goals** to get back to **normal life**



The **goals** may include **doing sport**



It is important to **keep active** after stroke

This **helps rehabilitation**



This **helps general health**

The rehabilitation team will **encourage** this



A **physiotherapist** makes an exercise **plan**

This is for **after physiotherapy** has **ended**



They teach **how to exercise safely**



After a stroke

people **must not drive**



**for at least a month**

The **doctor decides** when to **drive again**



Some people go **back to work**

The therapists can help **plan**

**Parts** of a job **may be difficult**

They can **talk to an employer**

They can **teach ways to cope**

They know about **equipment that helps**



Some difficulties **don't improve**

**Technology** may help some people

There are many ways to use **mobile phones**

They may **help**

**Apps** may help



**Therapy will carry on** for a while

Then people **progress on their own**

**Family** or **friends** may help

Some people need **more support**

**A GP will know** where to get this



There are **organisations** that **help**

They give **support**



They **help with coping**

**Meeting others** with a stroke **can help**



The stroke **staff know** about **groups**

They give **information** about these **groups**



Some groups help **communication**



The stroke staff **support** people to go

They **encourage** people to go

  	<p>The staff arrange an <b>appointment</b></p> <p>This is <b>6 months after</b> leaving <b>hospital</b></p> <p>The staff <b>find out</b></p> <p><b>how</b> people are <b>managing</b></p> <p>whether <b>more help</b> is needed whether</p> <p><b>more therapy</b> is needed</p> <p>There will be another <b>appointment</b> like this</p> <p><b>6 months after</b> the first</p> <p>These <b>appointments</b> happen <b>every year</b></p>
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## The research story

### What is the research?

 	<p>We are doing some <b>research</b></p> <p>It is about <b>stroke and xxxx</b></p> <p>Research helps us <b>learn</b></p> <p>We need to <b>know</b> more about <b>how to help</b></p>
--	--

- Use the stroke story to broadly explain what happens in a stroke, and then to give information about the aspect of stroke for your research.
- Explain the problem, what question do you want to answer, keep it simple.
- Continue with the details of what will happen in your research. Use the drop down menu for the headings in the template.

Use some of the wording in this section as a starting point. It is not written as a complete story, it is a selection of phrases the user group has found easy to understand. There are examples of how to explain procedures; adapt them as necessary. The examples are a mix of styles and tone to give suggestions of what can be done. The image library may have some of what you need for supporting written explanations about each concept.

## Why me?

 	<p>You <b>have had a stroke</b></p> <p>You are a <b>carer</b> of someone who has had a stroke</p>
	<p>Your stroke affected your <b>communication</b></p> <p>You find it <b>hard to write</b></p>



You had **treatment** for your stroke in **xxxx**  
**Hospital**

## Who is doing the research?



The **manager** of this research is  
**Helen Rodgers**



The **main researcher** is  
**Gill Pearl**



The research is run from the **xxx**  
**university/hospital**

**NHS**  
**National Institute for**  
**Health Research**

The **National Institute for Health Research** is  
**paying** for this research



## Why are we doing the research?



There is **therapy** for coping after stroke

**Psychologists** give this therapy

We **don't know** enough about it

This **research** will help us to **learn more**

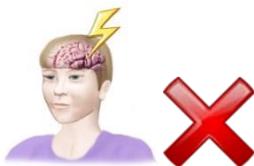


There is **a new drug**

This is for **shoulder pain after a stroke**

We need to **test this**

We **need to know more** about it

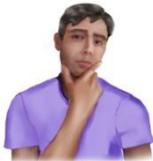


**How** can we **stop strokes** from happening?



Research can **test new** ways to give **therapy**

We can find out **what works** best



People **get help** after a stroke

Can we help people in **a better way?**

**You had help** after your stroke



**What was good?**



**What could be improved?**

After a stroke

some people **can't use** their **hand**



It is **hard** to **move** the **fingers**

**Occupational therapists** may **help**



They may **use a splint**

We want to try out a **new splint**



## After a stroke

some people have **pain**



## Medicine can help



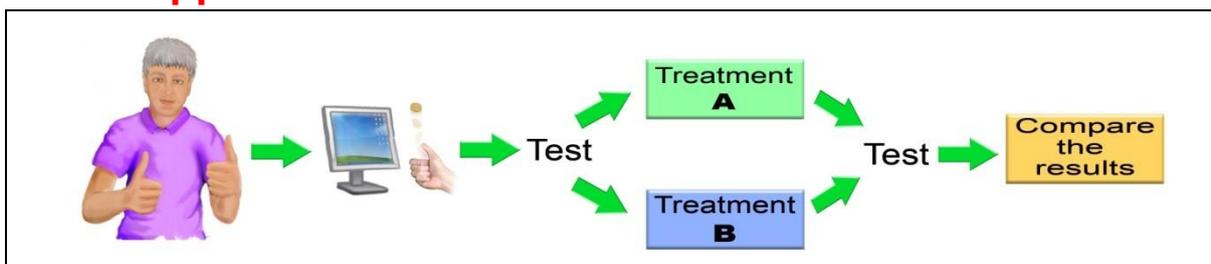
Usually the medicine is **3 times a day**

We want to know...



**Does it work once a day?**

## What happens in the research?



There are different ways of giving **treatment**

We want to **compare** two different ways

We want to know **which is best**

Treatment A is **XXX**

Treatment B is **XXX**

We want **200 people** to take part

**Half the people** will have **treatment A**

**Half the people** will have **treatment B**

The **computer decides**

This is like **flipping a coin**

You would **not know which** you get

You will have **some tests**





You will have **the treatment**

This will last **for xxx months/weeks**

Then you will have **more tests**

The researcher will **look at the results**

They will **learn** about the treatment



We want to **talk to xxx people**

We will **ask about xxx** after their stroke



We will use what they tell us



Then we will **learn more**

**What will I have to do?**



In the research you will

have an **interview**



**answer** some **questions**



**share** your **opinions** and **ideas**



have some **assessments**



do some **exercises**



share **your ideas**



learn **new ways** of doing things



use **equipment**



have some **tests**



We will give you a **questionnaire**



We will send you a **questionnaire**



You can do this **at home**

**Tell us if you need help**



We will **help you**



We will take **photographs/video recordings/sound recordings**



This helps us to **remember** what you said



This helps us to **measure** any **change**

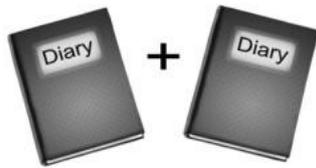
**Only the researchers** will **see** the  
photographs/video

They will be kept **safe**

## Where will the research happen?

 	<p>The research will happen in <b>several hospitals</b></p> <p>These hospitals are in the <b>UK</b></p> <p>The research will happen in <b>Newcastle University</b></p>
  	<p>You will need to <b>stay in hospital</b> for this research</p> <p>You will stay for <b>1 day</b></p>
	<p>You will need to <b>visit hospital for</b> the research <b>appointments</b></p> <p>You will <b>not stay overnight</b></p>
	<p>You will <b>go to a clinic</b></p>
	<p>A researcher will <b>visit</b> you at <b>home</b></p>

## How long will the research last?



The **whole research** will last for **xxx**  
**years/months**

**Your part** will last for **xxx years/months**

You will have **appointments every xxx/once**  
**a week/month**

## Will I get paid?

  	<p>You will <b>not get paid</b> for taking part in the research</p> <p>We will pay for <b>your travel</b> to any appointments.</p> <p>We will <b>pay</b> for any <b>expenses</b> for attending the appointments</p> <p>We will give you <b>vouchers</b> if you take part</p> <p>We will give you some <b>money</b></p> <p>This is to <b>thank you</b></p> <p>Some <b>appointments</b> will last a <b>long time</b></p> <p>We will give you <b>meals</b></p>
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## Do I have to take part?

 	<p>You can <b>decide</b></p> <p>You <b>don't have to</b></p> <p>If you don't take part you will <b>still get your normal help</b></p>
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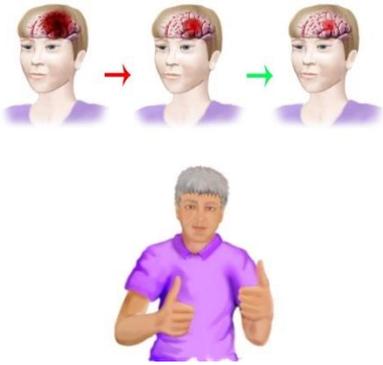
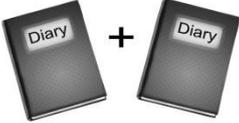
  	<p>If you change your mind, <b>you can stop</b> at any time</p> <p>You <b>don't</b> have to <b>give a reason</b></p> <p><b>If you stop</b> you will still get your <b>normal help</b></p>
  	<p>You don't have to decide now, you can <b>think about it</b></p> <p>You can <b>take your time</b></p> <p>You can <b>read</b> the information <b>again</b></p> <p>You can <b>talk to your family</b> to <b>help you decide</b></p>
	<p>You will need to <b>decide today</b> if you want to take part</p> <p>This is <b>because</b> xxxx</p>

## Who will see the information about me?

	<p>We will keep the <b>information</b> about you <b>safe</b></p> <p><b>Only</b> the <b>researchers</b> will see the <b>information</b> about you</p>
 	<p>We may <b>share</b> your information with <b>other researchers</b> in this <b>country</b></p> <p>We may <b>share</b> your information with <b>researchers</b> in <b>other countries</b></p> <p>This <b>helps</b> with <b>other research</b> about <b>stroke</b></p> <p>We will <b>take out your name</b> and <b>personal details</b></p>
	<p>We will <b>tell your doctor</b> that you are in this research project</p>



**What might be good about taking part?**

	<p>You <b>may be helped</b> by the therapy/treatment</p>
	<p>You may <b>enjoy</b> taking part</p>
	<p>You may find it <b>interesting</b></p>
	<p>You will <b>help</b> people in the <b>future</b></p> <p>They will get <b>better help</b></p>
	<p>You will help us to <b>learn</b></p> <p>This may <b>prevent strokes</b> in the <b>future</b></p>



**What might be difficult about taking part?**

	<p>We <b>don't think</b> it is <b>dangerous</b></p> <p>however</p> <p>the <b>therapy may not help</b> you</p>
	<p>There <b>may be</b> some <b>side effects</b></p>
	<p>You may find it <b>tiring</b></p> <p>You may find it <b>distressing</b></p> <p>It will <b>take</b> up <b>your time</b></p>

**What if I don't take part in the research?**



You will still get your **normal help**

## Is the research safe?

  	<p>A committee <b>decides</b> if research can <b>happen</b></p> <p>This is the <b>ethics committee</b></p> <p>They say that <b>this research can happen</b></p> <p>They say that it is <b>safe</b></p> <p>They say that it has been <b>planned properly</b></p>
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## What if something goes wrong?

	<p>This is very <b>unlikely</b></p> <p>However,</p> <p>The NHS has set up <b>a committee</b></p> <p>This committee will <b>monitor the research</b></p> <p>The committee has <b>different people</b> from those who do this research</p>
   	<p>If you <b>take part</b> in the research</p> <p>and <b>if you think</b> you were <b>harmed</b></p> <p>there are <b>people to talk to</b></p> <p><b>contact xxxxx</b></p> <p>at <b>xxxx</b></p> <p>The University has <b>insurance</b></p>

**What will happen after the research?**

	The <b>researchers</b> will <b>look at the results</b>
	They will <b>learn more</b> about <b>xxx</b>

## What will happen to the results?

	<p>We will <b>give you the results</b> of the research</p>
  	<p>We will share the <b>results</b> with <b>other researchers</b> at <b>conferences</b> and <b>meetings</b> through <b>newsletters</b> and <b>magazines</b> in <b>academic journals</b> on the <b>website xxxx</b> with <b>other people</b> who have a <b>stroke</b></p>
	<p>The results will <b>not use your name</b></p>
	<p>The results may include <b>what you said</b> but <b>not who said it</b></p>



The results may include **photographs of you**

## What next?

	<p>Do you <b>want</b> to <b>take part</b>?</p> <p><b>You need to decide</b></p>
 	<p>You may want <b>more information</b></p> <p>Contact <b>xxx</b></p> <p>They will <b>answer your questions</b></p> <p><b>Let us know</b> if you want to take part</p> <p>You can <b>contact us</b> at <b>xxxx</b></p>
 	<p>If you decide to take part</p> <p>you will need to <b>sign a consent form</b></p> <p>This says that <b>you understand</b> the research and <b>you agree</b> to take part</p>
	<p>We will <b>contact you</b></p> <p>We will ask for <b>your decision</b></p>

	<p><b>Yes</b> I want to</p> <p><b>No</b> I don't want to</p>
	<p>If you decide to take part</p> <p>you will have <b>an appointment</b></p> <p>This <b>appointment</b> will be in <b>xxx weeks</b></p> <p>At this appointment you will <b>xxxx</b></p> <p>The appointment will <b>last for xxxx</b></p>
	<p>You will need to <b>bring</b></p> <p>a <b>list</b> of your <b>medicines</b></p> <p>your <b>splint</b></p> <p>your <b>carer</b></p> <p>your plan of <b>therapy goals</b></p>

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## Appendix

### Taking *informed* consent – check list

#### Providing information:

1. Eligible patients to be given information sheet by member of clinical team, along with a verbal explanation of the study and what it would involve for them
2. To select the most appropriate form of information sheet, it is important to be aware of the amount of information the patient can understand (through being spoken to or reading written material)
3. Give patients time to decide (see protocol for how much time required for individual trial).

4. If patient is interested in participating, call member of team eligible to take consent for this study.

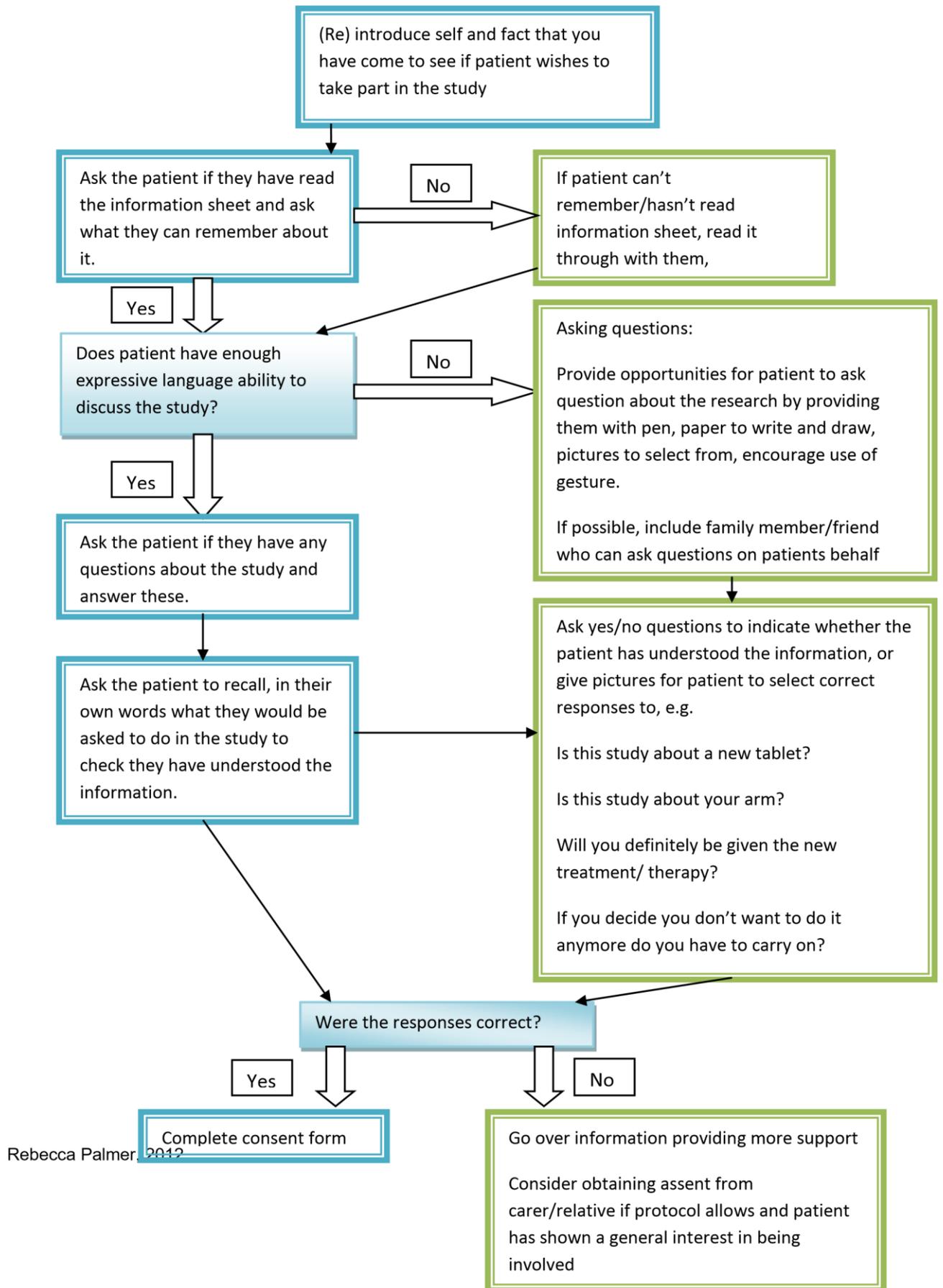
#### **Making sure the consent is informed:**

1. Introduce self and fact that you have come to see whether they are interested in taking part in the study
2. Check with the participant that they have read the information sheet and ask what they can remember about it
3. If they are struggling to remember/appear not to have read it fully, go over the information sheet with them again, reading/summarising each point
4. Allow the patient to ask questions. If the patient has impaired language skills, offer support by providing pen and paper to write or draw, show relevant pictures for them to select from, encourage use of gesture. If possible, have a member of family or a friend present who can ask questions on the patient's behalf
5. If the patient has sufficient language ability, ask them to tell you in their own words about what they would need to do if they took part in the trial
6. If they struggle with receptive or expressive language, ask yes/no questions about the information they have been given
7. If questions are answered incorrectly this suggests the person does not understand and any consent taken would not be *informed*. You need to make a judgement at this point as to whether the patient can provide their own consent with more time for discussion/use of supportive materials, or whether assent needs to be considered if the protocol allows.

#### **Completing consent form:**

1. Check consent form matches the date/version of information sheet
2. Make sure the patient reads each sentence in the consent form (you may need to read each one to them)
3. Ask the patient to *initial* each box
4. Make sure the patient signs and dates the consent form
5. If they are unable to do this, they can make a mark and have a carer/person not involved in the study witness their mark
6. Store one copy in the site file, one in patient notes, one for patient to keep.

#### **Informed consent flow diagram**



Rebecca Palmer, 2012

  
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