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Including People with Communication Disability in Stroke Research and Consultation

A Guide for Researchers and Service Providers

Published by

Connect – the communication disability network

Including people with communication disability in stroke research and consultation

A guide for researchers and service providers

This guide aims to help those interested in carrying out inclusive stroke research and consultation. It provides ideas and practical examples of including people with communication disability in all stages of the research process.

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About aphasia

Aphasia is a communication disability which occurs when the communication centres of the brain are damaged. It is usually caused by stroke, but can also be the result of head injury or tumours.

Each person with aphasia experiences it differently. Some people cannot speak at all, others can no longer read, write or use numbers. Everyday activities such as having a conversation, answering the phone, watching television, may suddenly become a source of profound frustration and anxiety both for the person with aphasia and for their families, friends and carers.

About Connect

Connect is a national charity working collaboratively with people with aphasia to provide practical, creative and lasting solutions. Connect promotes effective services, new opportunities and a better quality of life for people living with aphasia. We aim to enable people living with aphasia to:

- reconnect with life again
- have a voice in the wider community
- have access to a wide range of appropriate therapy and support

All proceeds from our publishing are used to support our work.

Introduction/How to use this guide

This Connect guide explores the issues faced by researchers and service providers interested in stroke research and consultation. It addresses issues raised when wanting to include people who have communication disability following stroke. Most of the advice contained within this publication relates to people who have aphasia. At Connect we feel that it you are able to make changes that include people with aphasia you will have made your research and consultation accessible for most people with communication disability more broadly.

All the information here comes from the professional experiences of a wide range of people, all of whom have been involved in research and consultancy that has included people with aphasia over the course of many years. We have gathered together a wealth of ideas and suggestions and, in this guide, will share them with you.

To exemplify what is said within the guide, we have included a variety of artefacts in the back of the publication. Taken from many sources, these artefacts demonstrate the suggestions made. They show a range of what accessible documents can look like.

1. Inclusive stroke research and consultation: what are the issues?

This Connect guide explores the issues faced by researchers, clinicians and service providers who aim to make their stroke research or consultation inclusive of, and accessible to people with communication impairments. Whilst, for researchers, scientific investigation remains the primary focus, stroke service providers are becoming increasingly engaged with research and consultation as part of their role. More clinical projects can range from small-scale, focused investigations to participation in comprehensive clinical trials. In addition, the emphasis on user-involvement in health-care means that more service providers are consulting patients and clients and involving them in the audit and development of stroke services.

Whatever the nature and scope of the project, it has been widely recognised that people who have communication impairments such as aphasia (about one third of the stroke population) tend to be excluded (Williams et al 1999). The reasons for this appear obvious. They may have difficulty understanding, processing and generating both spoken and written language. It can be hard to engage them in assessments, evaluations, tests, surveys, interviews, questionnaires, reports, discussions and all the other tools commonly used by stroke researchers. Their responses may seem invalid, unreliable, misleading or difficult to interpret. They can seem difficult to talk to and may appear not to understand or follow instructions and requests. Communication with this group of people can take up a lot of time; a rare commodity in hard-pressed research programmes or when service providers are attempting to fit consultation around clinical practice. Such difficulties lead many stroke researchers to give people with aphasia a wide berth, even though this means letting go of around one third of their potential research participants.

However, the culture of stroke research in the UK is changing. At the launch of the UK Stroke Research Network in September 2005, patient involvement in stroke research was described as being of central importance. This is in line with current health policy in the UK and can be seen as part of a more general movement towards 'user-led' and 'user-controlled' research which is slowly gathering impetus. The Department of Health funds an organisation called INVOLVE (www.invo.org.uk) whose remit is to foster public involvement in health, social care and public health research. INVOLVE's work reflects how user involvement in research is gaining strength. Many major funders, including the research councils, now stipulate some degree of user involvement in research projects. Researchers submitting bids are expected to give an indication of how this is going to be achieved (Department of Health 2005, *Research Governance framework for health and social care*).

Such developments may be challenging to a research culture that focuses on medical issues concerning the causes of, and treatments for, stroke and as such is rooted within traditionally scientific methods. In some quarters, user-involvement is regarded with suspicion, a distraction from the real business of research and a possible threat to the objectivity of traditional methods. Some stroke researchers remain to be convinced of their value.

However, as user involvement becomes central to current policies and funding initiatives in health and social care, and is increasingly in line with principles of research governance and anti-discriminatory legislation, you may find that it becomes one of the **requirements** of research funders, managers and ethics committees, rather than being an optional extra. You can cite relevant policies and initiatives in your proposal to give added impact. Drawing on the ideas and examples given in this Connect guide, you should be able make a convincing case for making your research accessible and inclusive, to everyone's benefit.

Within the guide we will use the term ‘research’ to refer to any project that seeks to explore or evaluate an aspect of stroke care be it clinical or academic, a funded Randomised Control Trial, a patient satisfaction project or an event that seeks to gain the views and aspirations of service users. When referring to the involvement of people with communication disability within projects, this participation could cover a range of type of involvement. People with communication disability could be involved as:

- information givers
- advisors
- consultants
- steering groups members
- co-researchers

Why involve people with communication impairments in stroke research?

The benefits of user involvement in research are generally well-rehearsed. Involving users leads to innovative and more relevant research that is more likely to be engaging, useful to, and use-able by, the people it concerns (Department of Health, 2006a, *Best research for best health*). It brings gains to those who contribute and collaborate and opens up a wealth of new ideas and possibilities to researchers (Tallon, Chard & Dieppe 2000). As a stroke researcher, all these benefits apply. Additionally, however, perhaps one of the most striking benefits of involving people with aphasia in stroke research is that this necessitates clear conceptualization, clear planning and clear communication. Such clarity enhances the quality of your research project and extends the reach of dissemination.

Equally, by involving people with communication disability in stroke research you as a researcher will benefit. You will be keeping up with developments and imperatives in health research and your work will be in line with anti-discrimination legislation. Your research and the way you communicate it will be clear.

The benefits do not mask the fact that it is hard to involve service users in research, and doubly difficult when communication is a struggle. The threat of tokenism is palpable, and many researchers and service providers quite simply feel they lack the practical skills to make inclusion work.

This is why we have produced this Connect guide: to promote researchers' practical communication skills and to promote reflection on the social relations that underpin research. In recent years, Connect has been involved in many different research projects, both directly and in an advisory capacity. In the course of these projects, we have learnt many valuable lessons. Some concern the practicalities of how to involve people with aphasia as research participants. Some concern the planning and preparation that enables people with aphasia to act as research advisors or collaborators. We have learned that if research is made accessible to people with aphasia it becomes more accessible to the wider community of people with stroke, and to everyone.

The main purpose of this guide is to share practical ideas gleaned from people involved in both sides of the research process (those carrying out, and those participating in research).

In the appendix you will find a number of artefacts that demonstrate the principles outlined in the text. Some have been reduced in size to save space.

2. Understanding communication impairment

Some researchers involved in stroke projects have told us that one of the barriers to making their research or consultation inclusive is the fact that they know relatively little about the impact of communication impairment on a person's ability to engage with assessment, questions, discussion and decisions. Investigators are aware that communication impairment is a complex matter and are aware that there is a spectrum of different types and severities of communication impairment, often with a variety of causes and prognoses. But some researchers may feel at a loss when faced with someone who has a communication impairment, particularly when this is not their field of expertise.

Teaching stroke researchers at Connect, we use a framework to explain and demystify communication impairment. This provides both a straightforward explanation and the basis for developing practical solutions to communication problems. We find that using this framework enables them to approach people with communication impairment more confidently.

Message in and message out

Communication can be divided into two separate processes**:**

1. getting the **message in** and
2. getting the **message out**

In order to get a message **in** (to understand and make sense of something that is said or written), a person needs to be able to do a number of things:

- See
- Hear
- Listen
- Read
- Understand
- Think

In order to get a message **out** (to express oneself in some way) a person needs to be able to:

- Think and formulate a message
- Find the words that express thoughts accurately
- Put words together into phrases or sentences
- Produce speech sounds or write
- Gesture or draw

Many conditions affect or disrupt a person's ability to get the message **in**. These include:

- Hearing impairment (difficulty hearing spoken words and intonation)
- Visual impairment (difficulty seeing the written word, facial expression and gesture)
- Aphasia (difficulty processing and understanding what is said or written)
- Dementia (difficulty understanding and formulating thoughts)

Conditions that affect a person's ability to get the message **out** include:

- Dementia (difficulty remembering and organising thoughts)
- Aphasia (difficulty finding the right words, putting words together and finding the right sounds or letters)
- Motor problems (paralysis, weakness or poor co-ordination due to conditions such as Parkinson's Disease, Multiple Sclerosis, Motor Neurone Disease). This can lead to slurred or indistinct speech and difficulty manipulating objects such as a pen or keyboard.

Many people who have a stroke will experience both aphasia and some motor impairment. So, they may have difficulty both understanding and formulating spoken and written language and also producing clear speech sounds and writing. In addition, they may have hearing or visual impairments, perhaps associated with ageing and nothing to do with the stroke. Table 1 summarises the main characteristics of different communication disabilities associates with a range of aetiologies.

What can you do?

However daunting communication problems appear to be, there are some simple techniques that you can use to enable the person with communication disability to get the message in, and get the message out. This use of techniques is called 'supported conversation' (after Kagan 1998).

TABLE 1 – Characteristics of communication disability

Cause of communication impairment (pseudonyms or type)	Possible causes	What is affected?	Message in compromised	Message out compromised	MAIN characteristic
Aphasia Dysphasia Broca's, expressive, non-fluent, anterior Wernicke's, receptive, fluent, posterior Global	Stroke, head injury, cerebral tumour, progressive aphasia,	**Language**	√	√	Word finding difficulties (either lots of 'empty' words or few words)
Apraxia Dyspraxia	Stroke, head injury, cerebral tumour etc.	**Speech** (coordination)	X	√	Groping for speech sounds
Dysarthria Anarthria Flaccid, spastic, ataxic, dyskinesic, extra pyramidal	Stroke, head injury, cerebral tumour, Parkinson's disease, multiple sclerosis, motor neurone disease, myasthenia gravis, cerebral palsy etc.	**Speech** (clarity and strength)	X	√	Weak-poorly controlled speech, voice and/or respiration
Dysphonia Aphonia	Laryngeal tumour, stroke, Parkinson's disease, multiple sclerosis, motor neurone disease, myasthenia gravis, vocal abuse, psychological factors etc.	**Voice** (laryngeal strength, pitch, quality)	X	√	Unusual voice quality
Dementia	Alzheimer's disease, pick's disease, multiple strokes, Huntingdon's disease, Parkinson's disease, head injury, progressive aphasia, cerebral tumour, acute confusional state etc.	**Cognition**	√	√	Confusion

To help get the message IN:

- Make sure the person is wearing glasses, if appropriate, and that any hearing aid (if used) is working and switched on
- Slow down your pace of speech
- Write down key words for the person to see (the important words only, not whole sentences)
- Keep your sentences simple - one idea per sentence
- Repeat and rephrase
- Summarise and recap at regular intervals
- Use drawings and diagrams to convey ideas. It doesn't matter if drawing is not your strong point - stick figures and simple outlines will do. Keep these to hand for reference in the conversation
- Check out that the person understands as you go along, using your drawings and key words to re-focus the discussion.
- Write a record of what is being agreed
- Cut down distractions
- Use natural gesture, body language and pointing to back up your message
- Use communication props and ramps such as photographs, maps, magazines, newspapers. You might want to develop diagrams to try and convey a particular concept. (These are the communication equivalent of physical ramps, something that helps a person get into a conversation or discussion)

To help a person get the message OUT:

- Model using pen and paper to write and draw key points and encourage the person to do the same. Some people with aphasia can write or draw enough to give you a clue.
- Encourage the person to make use of the words you have written down and your drawings. They might point to them, underline them, cross them out, and this will tell you a lot.
- Write down the key points of the conversation as you go along and use these as a constant reference point.
- Don’t rush. Be silent and give extra time to the person.
- Ask questions – move from general areas to more specific topics (‘Are we talking about people? Family? Your wife?’)
- Check out that you are understanding correctly on a regular basis (‘Have I got this right?’)
- Use props and ramps – maps, newspapers, photos, life books.
- Alphabet cards…take care - there are few situations in which they are useful. Many people with aphasia find them difficult to use. If the person has no aphasia, but has motor problems, they may be able to use these.
- Electronic aids… take care - many people with aphasia find them difficult to use. People without aphasia may be able to use them.
- Stay calm and relaxed.
- Don’t pretend you understand. If there is total communication breakdown, be honest and acknowledge the fact that both of you are struggling. Secure the person’s agreement to leave the point and move on to something else. You may suggest returning to the point later on (this often helps) but remember to do this if so.

When you encounter someone who has a communication impairment, there are **four questions** you should ask yourself:

1. Does this person have any difficulty **getting the message in**?
2. Does this person have any difficulty **getting the message out**?
3. **What helps** get the message in and out?
4. **What doesn’t help**?

Being honest and creative in how you communicate, and being calm and flexible in trying things out, you should enable the person with communication difficulties to engage with what you are saying and the issues you want to cover in your research. By developing **your communication skills** you can make it possible for the person to take part and make a contribution to research.

Using your time well

Clearly, this approach to communication will be time-consuming. It is important to anticipate this, and to arrange extra time for encounters with people who have a communication impairment, so that you can find out what helps and so that you are not rushing or pressurising the person or yourself.

Here are some ideas about being prepared and managing the time issue to the best effect:

- Be clear and explicit about the need for extra time in advance, with everyone involved. Extra time invested will be time well spent.

- If possible, spend the first session getting to know the person and their communication requirements and preferences. You may be able to supplement this information by talking with carers and therapists.
- Try to ascertain whether there is a good (or bad) time of day for this person. Tiredness, or perhaps side-effects from medication, may mean that the person prefers to come to a meeting or take part in an interview in the morning or later in the day. It's also important to try and clarify the person's weekly timetable so that you can avoid clashes, confusion and conflicts of interest.
- Back up any verbal arrangement with clear written and/or pictorial documentation.

Remember this additional time commitment is really worth it. If successful, you avoid wasting time on unproductive, frustrating interviews and you access an otherwise inaccessible 30% of your research sample.

In the next chapter, we look at how some simple changes to written project information and administration will enable you to make your research more accessible.

3. Information, consent and administration

Sampling and finding people with communication impairments

Finding people to take part in any research project can be a challenge, but the challenges multiply when potential participants struggle to understand, read, write and talk. People with aphasia may not be able to follow fliers and information sheets about the research, and be unable or reluctant to put themselves forward, if this depends on phoning or writing. As a result, you may decide to purposively sample people with communication impairments, to ensure that they are definitely represented in the group you are studying, and not excluded. This means setting a quota of numbers of people with communication impairments in your research cohort, and making every effort to try and fill this.

However, people with communication impairments can be hard both to locate and sign up to research. You can minimise some of these problems. Be proactive in locating and making contact with possible participants. You can make a start by going through networks that commonly provide services for this group by giving you the opportunity to meet and talk to people with communication impairments so that you can tell them about the project:

- speech and language therapists
- rehabilitation organisations
- voluntary sector organisations dedicated to people with stroke (such as dysphasia support groups run by the Stroke Association, Different Strokes, Chest Heart and Stroke Scotland *see* Chapter 7)

- disabled peoples' groups
- self-help groups (e.g. Speakability)

They may be able to make some initial suggestions. You might have the opportunity to give a short presentation about the project and attract interest. To help make this accessible use the 'message in' techniques discussed in Chapter 2 and look at the group facilitation skills described in Chapter 5.

You will have to get ethical clearance for making this approach. Ethics committees will want to see evidence that you can explain the project in a clear way that people can understand, and enable them to make an informed choice about whether or not they wish to take part (Central Office for Research Ethics Committees (COREC) is a useful source of information – see chapter 7). In our experience, ethics committees are often impressed when efforts have been made to produce clear, easy to follow information.

Accessible information: making it clear

Project information, expressions of interest, consent forms, in fact any written material concerning the project can be made accessible for people with aphasia who might have difficulty reading and understanding standard format.

Here are a number of ideas for making written information easier to follow:

- 👍 Remove all jargon and acronyms. Use straightforward language, as if you were addressing the person directly.
- 👍 Try to keep to one main idea per sentence.

- Use active, not passive language for example: ‘You will take part in an interview’ not ‘you will be interviewed.’
- Bullet points can really help and can be less off-putting than blocks of text.
- Organise your document clearly. Headings, sub-headings, page numbers and contents lists can help the reader navigate through the document.
- Question and answer formats can make an information sheet more user-friendly.
- People with aphasia have told us that using a plain, clear font is really helpful. We suggest sans serif font (Ariel is good, others include Helvetica, Avant Garde, and Geneva), lower case, 14pt or more with 1.5 spacing.
- Make sure your pages are not too cluttered or busy. Aim for plenty of white space.
- Adding pictures or diagrams can really help get your message across, but they must be relevant and respectful. Take care not to over-design documents; pages that are cluttered with imagery are off-putting.
- Provide summaries of key points - you might want to signal their importance by highlighting them or putting them in a box.

Following these principles will help you make your project information accessible. But they will also be useful when you prepare other documents in the course of your research - in fact **anything at all** that you want people with aphasia to read. This includes:

- appointments and other administration
- letters (including those sent to others but copied to your research participants)

- questionnaires
- websites
- surveys
- feedback
- agendas
- briefing notes
- minutes
- reports and other forms of dissemination.

Accessible information obviously takes up more space than information presented in a standard way. Rather than trying to condense project information onto one sheet, we have tended towards developing information booklets or leaflets.

You can find two examples of parts of accessible information sheets in the appendix at the back of this guide (see artefacts 1 and 2).

Consent forms

Can your consent forms be filled in by someone with aphasia? You will need to break down each component that you are checking out and asking consent for. As a matter of course, try to provide plenty of space for people to write. Many people with aphasia have motor impairments and may have to write with their non-preferred hand.

Using tick boxes plus ‘thumbs up’ and ‘thumbs down’ images can help people to understand what you are asking them about and remove the stress of trying to fill in a form (see artefact 3). If someone has difficulty writing their name, they may wish to make a mark such as a cross. It is important that this is witnessed and signed by a third person.

Artefacts 3 and 4 exemplify how consent forms can be adapted to facilitate more informed consent for people with communication disability.

Here are some examples of accessible project information and consent forms taken from a number of different projects. Artefacts 5 and 6 give an example of project information and consent form in its original state, and then after being re-worked to make it suitable for people with aphasia.

The process of giving information and gaining consent

Changing the content and layout of written documents is not automatically going to make them fully accessible for people with communication impairments. Clear material needs to be supported by a clear process of giving information. This means going through the information with the person, step by step, and checking that they understand each section. This process can be extremely useful, as you can get to know the person and learn something about their communication requirements and preferences. You can develop and try out your own skills in supporting communication, identify potential trouble spots, and establish a good relationship with the person with aphasia. This process will also save you time in the long run when you come to interview or meet with the person with aphasia as you will know something of what to expect.

This next example (artefact 7) shows how the process of giving information and gaining consent can be made accessible by using an unusual mode of communication. The researchers in this study prepared a PowerPoint presentation that enabled them to explain each aspect of the project, on one slide at a time, to gain fully informed consent through an informal interview.

Getting the right tone in your information

When you check through your information and documents related to research, take a moment to check the tone of voice. It's very important to be positive and to approach your readers as equals. Your tone should be warm, welcoming, straightforward and respectful. Medical or academic jargon can have a very negative impact and be off-putting as Grace (who has aphasia) reported when she followed a link to a piece about a research project on an aphasia-related website. All had been accessible until the research project.

'Not good if you're trying to understand your own illness. It makes you feel even more foolish because you're trying to understand and they're not letting you in on it. The rug is pulled from under your feet. You feel you're doing something by logging on, gaining control; this is almost like a big sign saying 'no, you can't come in here'.'

Keeping people informed

Try not to think of information-giving as a one-hit wonder – something that only happens at the beginning of a project. Use supported communication – the ideas for producing clear and accessible documents outlined above - to keep your participants informed and engaged as you go along. It is really worth re-visiting the purpose and aims of the project at regular intervals (even if this seems repetitive) as it helps people keep a firm grasp on the research and on their role in it (Kagan 1998). You may also want to keep people up to date with emerging findings or explain more theoretical aspects of your project. This, too, can be done accessibly, using simple communication ramps, as these examples show.

Artefact 8 demonstrates how complex information can be made more accessible to enable discussion with research participants and advisors.

Administration and correspondence

Appointment letters are a good example of project administration that needs some thought. You want the person with aphasia to arrive at your venue, or to expect your visit, on the correct day at the correct time.

Here are some ideas to help you make your correspondence clear and effective:

- Arrangements as clear and straightforward as possible
- Be aware of any difficulties that people with aphasia might encounter in terms of arranging and using transport to get to your venue. Providing a map, information about transport links and a contact phone number is useful.
- Call the day before to confirm that the person is expecting to attend.

- Give your project a user-friendly name and develop an icon that will symbolise it. Used consistently in every piece of correspondence this will help the person to identify and relate to the project more quickly. An example of this is given below.
- A photograph of the person from whom the letter is sent, plus a contact number, is also useful.

'The Communication Access Toolkit' is a project we are running at Connect (supported by The King's Fund). This name is a bit of a mouthful, and may be difficult to understand, so we have changed it to 'The Way In Project' (because communication access is the *way in* to involvement). We symbolise the project with an image of an open door. We use this title and image consistently in every piece of correspondence with the people with aphasia who are involved as advisors on the project.

Artefact 9 shows how some of these suggestions have been implemented.

4. Interviewing a person with aphasia

As part of your project, you may need to conduct an interview with a person who has aphasia. Again, thinking ahead will allow you to create the best conditions for the person with aphasia to contribute and make the best use of your time. Here are some of the things you need to think about in advance of the interview session:

? Have you negotiated a quiet place to do the interview? No TV, no phone calls, no radio, no other distractions?
? Have you arranged the best time for the interview e.g. when the person is not likely to be tired or when the person's children are at school?
? Have you arranged some extra time for this interview, so that you can go at a slower pace?
? Have you negotiated the time needed with everyone concerned?
? Have you been clear about how long the interview will take and who is going to be involved?
? Have you found out as much as you can in advance about what helps get the message in and out?
? Do you know how the person's communication aid, if s/he uses one, works?
? Have you brought along plenty of paper and pens and a clipboard?
? Have you thought ahead and prepared some ramps to help you explain your project and any difficult concepts or ask complex questions?

Artefact 10 is an example of this type of ramp. This ramp was used to support making a video for training. It enabled the facilitator to discuss the purposes of the meeting and the group members' experiences of hospital care. The first sheet was an information sheet. The remaining sheets were ramps used during the discussion.

What about standardisation?

Stroke researchers who have to administer a standardised assessment or interview may, of course, encounter problems in making these accessible for people with aphasia. Obviously altering the presentation or format of a standardised tool threatens the validity of the instrument. However, it may be preferable for you to employ a more flexible approach with this sub group of research participants, rather than exclude them from taking part. An argument you can use when justifying using of non-standardised tools (or modifying standardised ones) is that it is better to widen the data-set by including some un-standardised but accessible and acceptable, data.

Artefact 11 shows how part of a standardised tool can be modified to improve its accessibility and acceptability to a wider range of people. (These scales are taken from *the Comprehensive Aphasia Test* – Swinburn, Porter and Howard 2004 and *the Communication Disability Profile* – Swinburn with Byng 2006).

Some researchers have made their standardised assessments accessible. This involves streamlining concepts, simplifying the language used and providing ramps, such as accessible visual analogue scales, that allow people with aphasia to understand what they are being asked about and to respond. Such scales are also extremely useful when soliciting feedback on the project from people with aphasia.

Remember, an assessment or interview that is accessible to people with aphasia will probably be accessible to most people, whether or not they have communication impairments. So by modifying your tools you are likely to be improving your research for everyone. Some examples of outcome measures that have been used successfully within stroke research, where attention has been paid to accessible design, include:

- The Communication Disability Profile (Swinburn With Byng 2006)
- The EQ-5D (EuroQol Group 1990)
- COOP-WONCA charts (van Weel 1995)
- The Communicative Effectiveness Index (the CETI) (Lomas 1989)
- The stroke and aphasia quality of life scale-39 (the SA-QOL) (Hilari 2004)
- Visual Analogue Self-Esteem Scale (VASES) (Brumfitt & Sheeran, 1999)
- Visual Analogue Mood Scales (VAMS) (Aitkin, 1969)
- Burden Of Stroke Scale – (Communication Difficulties) (Doyle 2003)

When things go wrong

When interviewing or talking with people who have aphasia the supported conversation - **message in** and **message out** techniques (described in Chapter 2) should help. However, despite everyone's best efforts, you and the person with aphasia may experience communication difficulties during a research interview, assessment or meeting. Stroke researchers tell us that they find communication breakdown alarming and sometimes don't know how to handle it.

Here are some of the most commonly encountered difficulties, together with some suggestions as to what you can do to deal with the situation:

What do I do when the person with aphasia has an unsuccessful struggle for words, becomes angry and frustrated and then gives up?

- Wait, keep calm, don't jump in.
- Slow down the pace of your exchange.
- Try to appear relaxed, even if you don't feel it.
- Try to locate the broad area of meaning, then home in on specifics (e.g. are we talking about a person – *then* – someone in your family – *then* – your wife?).
- Model drawing and writing yourself - and offer this as a prop for the person to use and respond to.
- Try using the phrase 'Some people say…' to give the person an idea to respond to. This can often relieve a frustrating search for words. (e.g. 'some people have told me they felt very alone in hospital. Is it the same for you?')
- Acknowledge the difficulties and the frustration, and show that you share responsibility for the problem.
- Acknowledge the person's competence: 'I know you know what you want to say'. 'I know this is an important point, something you feel strongly about.'

- Try not to get bogged down - keep the flow going. Keep the tone light. Sometimes humour can help, but be careful.
- Summarise where you have got to so far, using your written record, and negotiate moving on to another topic.
- Suggest leaving the troublesome topic and returning to it later.

My interviews with people who have aphasia go so slowly. We end up exhausted and both of us lose track. What can I do?

- Don't be tempted to rush and cover everything. This will lead to poor information and everyone wasting their time.
- Think about cutting down the number of topics you want to cover. Stick to the essentials.
- Don't be tempted to extend the interview. If you can see that the person is tiring, suggest that you return another time. Negotiate another appointment as soon as possible.
- If picking up an interview on a separate occasion, make sure you listen through the first interview just before you meet again. Re-cap for the person as a way of tuning him/her back in. It will really help if you can use some of the words and phrases previously used by the respondent. You might want to prepare some communication ramps to help you summarise what's been covered.

People with aphasia often become tearful and can seem very upset. What's the best way to respond?

- Make sure you keep calm and focused. Don't get upset yourself.

- Check out whether the person is really upset - sometimes people with stroke find tears and laughter difficult to control and these don't reflect how they are actually feeling.
- Acknowledge the person's feelings ('It looks like you are upset about this').
- Try not to respond in an overtly sympathetic way - this can make it harder for the person to re-establish control.
- If the person still talks despite crying, continue with the interview. If not, ask if they would like a short break.
- Be matter of fact and neutral. Don't make a big deal of the situation.
- Move smoothly onto a different topic, something more neutral.
- Try to keep the interview flowing. This will help the person to regain control and confidence.

I tried to interview someone with aphasia but she found it difficult to keep to the point and started going off at various tangents and talking a lot about things that weren't really relevant. What should I have done?

- If someone with aphasia goes off on a tangent and is talking a lot they may not be aware of, or able to control this. It can help if you lose eye contact with them. It is difficult, but try not to nod or respond to what they are saying. Glance down at your paperwork instead.
- When the person is talking about the topics you want to cover, signal your attention and interest very clearly. Lean forward, hold eye contact, nod.

- Practise using some standard phrases that will gently re-direct the person to the issue you want to address: ‘That’s a very interesting point, but I wonder if we could go back to…’
- If this doesn’t work, you may need to be more direct and assertive in re-focusing the discussion. Using gesture can often help - for example holding your hand up to signal ‘stop’ can reinforce what you are saying. You may want to mention the fact that time is moving on and that you have a few more things to cover.
- Narrow down your questions to specifics – what, where, when and who? Open questions may be too open.
- You may be able to stop the flow by re-capping and summarising, using diagrams and drawings. This will provide an anchor for the person and enable them to re-focus on the topic.

I started interviewing Mabel, a person with aphasia, and we were managing quite well although she has quite severe difficulties. However, her sister insisted on sitting in and kept on answering the questions herself. She didn’t give Mabel any chance to answer. I ended up with reams of material from her and virtually nothing from Mabel. I’m sure Mabel had different views to express, but I never got to hear them. What could I have done?

- Sometimes, understandably, relatives and carers can be very protective. Also they may think that the person with aphasia can’t communicate. They may also have different or conflicting views to the person with aphasia. Try to anticipate these possibilities when you arrange the appointment.

- Try to secure the relative’s agreement for you to interview the person alone. Maybe ask for hints and tips about what is helpful for communication.
- Before you start the interview, re-iterate that you want this time to talk with the person who has aphasia, and how long you will be.
- Sometimes people with aphasia feel more confident if a relative or carer sits in on the interview. If the relative starts contributing, acknowledge that they have issues that are interesting and important, and ask if you can talk about these later on, after the interview has ended.
- Model using good communication support.
- Keep your attention focused on the person with aphasia, not on the relative. Keep your questions directed towards the person with aphasia.

5. Making meetings work

Whether you are conducting focus groups with research participants who have stroke and aphasia, working with an advisory panel or reference group of collaborators or consulting service users, you will need to attend to the practicalities of making meetings work successfully. These practicalities concern the venue, transport, timing and structure of meetings, information and administration and of course, communication and the facilitation of the meetings themselves. Although they seem self-evident, paying attention to these details can make all the difference to whether your meeting results in meaningful or sub-standard data.

Research and consultation meetings: venues, transport and timing

Here are some of the practical steps that will help get your research meeting off to a good start:

- Find a venue with good physical access (toilets, lifts, ramps that are accessible to wheelchair-users)
- Choose a pleasant, relaxing venue that is not too clinical
- Think ahead about suitable venues - you may need to budget for room rental if your own accommodation is inaccessible or sub-standard
- Make sure transport costs, including taxi costs, are covered and group members know how to claim. You may need to offer support with this.
- Have a clear policy on paying participants, collaborators and advisors for their involvement. This is a thorny issue for many disabled people who fear losing their benefits if they receive

payment. For people with aphasia, complex verbal and written negotiations with benefits officers are very off-putting, and this can prove a massive barrier to involvement. The Department of Health has published some useful guidelines on payment (Reward and recognition – DoH 2006) but the situation is by no means clear or straightforward. However, it is helpful if you are clear about YOUR policy.

- Check communication access in the venue: clear signage; a quiet area to meet; plenty of room; a table and props such as paper, pens, flip-charts and clip-boards for drawing and writing.
- Choose a time that suits group members. People with stroke and aphasia may not want to travel during the rush hour, and also may tire quickly. We have found that a good solution is to organize meetings to span lunch-time, starting at 11am and ending at 3.30. This gives people time to have a coffee when they arrive, and then have a good break and a rest at lunch time.
- Provide high quality refreshments. This indicates that you value the contribution your participants are making.
- Develop clear terms of reference for the group. Make sure people know what they will be expected to do, what their role covers and what it does not cover (artefact 12 can be used to check that both parties are clear what will be involved).
- Negotiate an extended, more leisurely timetable for the meeting. We have learned that the customary high-speed, high-pressure research meetings, with crammed agendas and no breaks, can be counter-productive, excluding, and yield poor quality data.

- Decide with group members how often you will meet by discussing options. Sometimes holding a series of meetings closer together means that the impetus is maintained and group members keep track of what is happening.
- After the first few meetings check that the meetings work well for group members. Sometimes changes to the planned format can be useful.
- Provide clear, accessible agendas, directions, briefing notes, minutes, and discussion documents.

Artefacts 13 and 14 demonstrate accessible ways of setting agendas and ground rules.

Research meetings: communication and interactions

A successful research meeting needs significant group facilitation skills, as well as communication support for individuals. Here are some guidelines:

- Make sure you know who is coming and what support they are likely to need.
- Make room for communication supporters to sit next to a person with aphasia where necessary (this could be a member of the research team, a student or a volunteer).
- Ensure that communication supporters know what to do (message in and message out techniques). Sometimes people with aphasia welcome having key words written down as the meeting progresses. This helps to capture the points that are being made. Communication supporters also have the task of indicating when someone wants to make a point. Supporters

should be clear about whether they are simply acting as advocates, or whether they themselves are also meant to contribute to the discussion.

- Slow the pace of the discussion right down and monitor the language used to make sure it is as straightforward as possible. Sometimes group members who don’t have aphasia can find it difficult to slow down and simplify what they say, and you may need to offer them training.
- Set ground rules with the group before you start. These concern pace, jargon, giving people time, not interrupting and so on.
- One of the chair’s roles is to keep a watchful eye on proceedings, and to monitor whether or not ground rules are being observed. Towards the end the chair should also ask every group member to evaluate the meeting and to indicate any difficult or inaccessible moments.
- Keep a careful eye on everyone’s facial expression and body language. Being particularly aware of those who may find talking a struggle, it is important to ensure they are invited into the discussion on a regular basis. Sometimes this can be done indirectly, by picking up on body language and facial expression: ‘John, you look as if you don’t agree with that?’ Sometimes you may need to ask people for their opinion directly: ‘Are you happy with that idea Mary?’
- The chair can help to ‘anchor’ the discussion by summing up periodically: ‘So we have discussed this point and that point. And we have agreed that…’
- The chair can help group members to navigate the discussion by being very explicit in signalling when the discussion is going to move on.

- Writing points of agreement and discussion up on a flip chart, and trying to depict different views using key words and simple graphics can be an enormously helpful way of keeping everyone focused and in touch with what is going on. Someone other than the chair might take on the role of flip-charter.
- Make overt use of gesture and body language yourself. This enables you to 'conduct' the meeting without totally relying on language. For example, if a group member is talking a lot, a hand gesture to indicate 'stop' can help them to hold back, while the chair scans around other group members to invite contributions. Similarly, pointing to and resting the hand on key words and diagrams can also help the group to re-focus, if the point is in danger of getting lost.

When writing minutes for research meetings it is probably advisable to condense down the discussion and give summaries rather than a blow by blow account of every exchange. You may want to include boxes containing issues raised by particular group members, and possibly quotes. Try to keep a consistent format for the minutes as this, along with clear headings, will help group members keep an overview of the issues discussed from meeting to meeting.

The aim of all these suggestions is to theme and order information to ensure accessibility. The skill is to avoid 'dumbing down' or being patronising.

Artefact 15 is an example of how documentation and attention to process can support the inclusion of people with aphasia in research as it moves forward. In this project, the research team were given strong feedback that the original meeting was not working for them.

The original meeting included all advisers - both those with and without aphasia, and discussed all topics - including research methodology. A pre-meeting was therefore introduced for people with aphasia. This enabled them to contribute successfully during the full meeting and to leave when the topic of discussion was not within their sphere of expertise.

6. When the project ends: dissemination and evaluation

Throughout your project, you have tried to make every document and every piece of correspondence accessible to people with aphasia. What happens when the project ends? You will be planning to write a report, and will possibly want to produce some academic papers and perhaps book chapters on your findings and their implications. Are these outputs from your research going to be accessible to people who took part? The answer is probably not, whether or not the participants have aphasia. Academic writing can be dense and stylistically obscure, and different academic fields and disciplines draw on research traditions that are not usually open to the general public.

However, in keeping with the inclusive ethos of your research, you may want to consider make the findings, implications and application of your project accessible to those whom it concerns: participants, advisors, collaborators of course, and people with stroke more generally.

To write an accessible report, following the guidelines on producing clear information (Chapter 3) will help. Key issues are as follows:

- Boil down your findings to the key points
- Simplify your language: avoid academic jargon
- If possible find different, graphic ways of representing complex or abstract points
- Give lengthy documents a very clear structure. A table of contents, an index and headings can also help a lot.

- 👍 Present the document clearly, making it easy to find one's way around. We sometimes use folders with dividers and different coloured paper for different topics.

Knowing in advance that accessible writing can be time-consuming, you may consider negotiating extra time at the end of the project for this task when planning support for your project initially. If you haven't been able to negotiate the necessary time to produce your report in an accessible form, you may think about writing an accessible summary. This can be an extremely useful exercise as it demands that you are completely on top of your material and the key ideas you are trying to convey. This clarity should benefit all your presentations and writing as you spread the word about your project.

Think about the practicalities of producing accessible research reports if you are considering formal academic publication. This may be beyond the remit of standard publishers so look around for publishers and journals that have covered such work, for example Pavilion Publishing (www.pavpub.co.uk) and Disability and Society (Porter,et al, 2005)

Identifying in advance some of the practicalities and costs of producing alternative formats will enable you to make a convincing case for support from the start.

Artefact 16 is an example of more accessible form of research dissemination.

Written documentation may not be the only way to disseminate your research findings. Another way is to think **beyond the document**. You might suggest, for example, mounting a set of events, in which you give a summary and host a discussion (both accessible), and support question and answer sessions. As with the research itself, the organization and administration of such an event need careful attention, so that you can ensure that people with aphasia know what it is about, when and where it is, how to get there and what to expect. You will find the ideas for making research meetings work useful here (Chapter 5).

The benefits of making dissemination accessible

Accessible dissemination will enable your research to have an impact on the people whom it concerns: people with stroke and aphasia. It will open up your research to a much wider audience, and this in turn will bring many benefits in terms of generating relevant and useful feedback and innovative research ideas. Equally if the liaison has been mutually enjoyable then those people with stroke and aphasia are much more likely to participate in your future projects or become actively involved in contributing to service review and planning. In addition, from the researcher's perspective, producing an accessible account of your research necessitates clear conceptualisation and expression - an advantage for every researcher. Expressing complex ideas simply and making them meaningful without compromising can be a useful, rewarding process.

7. Conclusion, resources and bibliography

The involvement of people with communication impairments will enhance your stroke research or consultation, making it more representative of, and relevant to the broad spectrum of people who have stroke. Involvement can be challenging but brings many gains to researchers, collaborators, advisors and participants alike.

Thinking ahead about this issue will enable you to prepare proposals that give you the best chance of ensuring people with stroke and aphasia are involved at different levels, be it as information givers, advisors or as part of a steering group advising on the direction of the project. Whatever the level of involvement, don't underestimate the time needed for preparing, carrying out and disseminating inclusive research, and make a clear case for this in advance in your proposal. If you are working with people with aphasia as advisors or collaborators, it is well worth making a case for extra build-up and wind-down time for the project. If a person with aphasia is a co-researcher, make sure there is time and capacity within the project for training and on-going support. Make sure your research time-line can realistically accommodate these.

We hope this guide supports you in developing the practical strategies and skills for inclusive research and consultation more. Further ideas for widespread service level change can be found within the Connect training and publications programmes (www.ukconnect.org) along with resources, references and useful contact information that follow overleaf.

Resources and bibliography

Connect Training

Connect runs a number of courses that aim specifically to enable people researching into stroke and aphasia to do so in an inclusive fashion. Details of these courses are available in the *training section* of our website *www.ukconnect.org*

Examples of inclusive research projects

In developing this guide we have drawn upon a number of different projects with which Connect has been associated. Readers may wish to follow them up in more detail. They include:

The Discovery Project

Funded by Dunhill Medical Trust

Project aim

To investigate the impact of Connect therapy and support services on people with aphasia and their relatives

Involvement of people with communication disability

Four people with aphasia worked as advisors to the project. They were part of the overall advisory group They helped develop the accessible version of the project findings.

Further information

- van der Gaag, A, Smith, L, Davies, S, Moss, B, Mowles, C. (2005) Connect therapy and support services for people with long term stroke and aphasia and their relatives; a six month follow up study. *Clinical Rehabilitation*, 19, p372-380

- van der Gaag, A, Smith, L, Mowles, C, Davis, S., Moss, B. (2005) Therapy that makes the right connections. *Therapy Weekly*, June 9, 2005
- van der Gaag, A, Mowles, C. Understanding values in Anderson, C, van der Gaag, A. (2005) *Speech and Language Therapy: Issues in Professional Practice* London: Whurr publishers

The Communication Disability Profile project

Funded by NW Thames Research and Development grant, King's Fund Educational Bursary, PPP Mid-careers award and Connect

Project aim

To develop an accessible tool to explore the impact of acquiring and living with aphasia

Involvement of people with communication disability

Eight people with aphasia trialled an initial version of the tool. Subsequent development was guided by three people with aphasia through long term involvement in an advisory group.

Further information

- Chapter 6 'Social relationships of research applied to people with aphasia' Swinburn C.A. (2003) unpublished PhD thesis *Evolution of the concepts and methods associated with exploring and measuring the impact of aphasia.* City University, London
- *The Communication Disability Profile* (2006) Swinburn with Byng. Connect Press

Living with severe aphasia

Funded by The Joseph Rowntree Foundation

Project aim

To track the social exclusion of people living with severe aphasia.

Involvement of people with communication disability

Participants with severe aphasia took part in the field work (ethnographic observation and supported interview) and also attended feedback meetings to discuss the project findings. The project was steered by an advisory group comprising five people with aphasia of varying severity.

An accessible report was developed by one of the advisory group working in conjunction with the researcher. This has not yet been published.

Further information

- Parr, S. 2004 *Living with severe aphasia: the experience of communication disability following stroke*. Brighton, Pavilion.

The Taking Control Project

Funded by Department of health Section 64

Project aim

To increase opportunities for people with aphasia to take part in and lead self management activities

Involvement of people with communication disability

Two people with aphasia worked on the project team as advisors. Other people with aphasia helped to make self management activities more communicatively accessible through the development and use of communication ramps.

Further information

- alanhewitt@ukconnect.org or carolepound@ukconnect.org

Accessible Internet Technologies Project

Funded by the Economic and Social Research Council

Project aim

To identify the barriers and facilitators to Internet use by people with communication disability, and to explore the potential of the Internet as a means of self expression and making contact. The project was part of the ESRC Innovative Health Technologies Programme.

Involvement of people with communication disability

Thirteen people with aphasia took part in a working group. Meeting once a week over the course of a year, participants took part in group and individual Internet surfing, documented obstacles to Internet use, developed an accessible website and constructed personal web pages.

Further information

- Project findings are available on www.york.ac.uk/res/iht

Talking about Aphasia Project

Funded by The Joseph Rowntree Foundation

Project aim

To explore the experience of aphasia from the perspective of people who have it.

Involvement of people with communication disability

Fifty people with aphasia took part in in-depth interviews that explored their experience of communication impairment. Two people with aphasia took the roles of project co-worker and project consultant. Project findings were produced in non-academic form, as a book. Project findings were presented to groups of people with aphasia, as well as to academic and clinical audiences.

Further information

- Parr, S., Byng, S., Gilpin,S. with Ireland, C. (1997) *Talking about Aphasia*, Buckingham, Open University Press.

The Communication Access Toolkit Project

Funded by The King's Fund

Project aim

To develop a toolkit about communication access for providers of health, social care and voluntary services.

Involvement of people with communication disability

One person with aphasia is a paid project worker who monitors and advices on involvement issues. An advisory group of people with aphasia steer the project and are actively involved in developing the toolkit.

Further information

- susiepparr@btinternet.com

Other useful resources and contacts

Beyond Connect there are other resources and contacts that researchers and clinicians may find useful. Here are a few examples:

The Aphasia Institute, Toronto, Canada

This centre is at the forefront of championing the cause for inclusion of people with aphasia in a wide variety of arena. As part of this work they have produced some practical resources which enable clinicians and researchers alike to make their interactions more accessible and inclusive engage with people with aphasia. These include:

- Kagan,A., Winckel,J. and Schumway,E. (1996) *Pictographic communication resources manual*. Toronto, Aphasia Centre
- Kagan,A. & Shumway, E. (2003) *Talking to your …. Interactive resources for people and their health practitioners*
- www.aphasia.ca

The Stroke Association

Stroke Information Service
The Stroke Association
240 City Road
London EC1V 2PR
info@stroke.org.uk

Speakablility (formerly Action for Dysphasic Adults)

1 Royal Street
London SE1 7LL
Tel: 020 7261 9572
Fax: 020 7928 9542
e-mail: speakability@speakability.org.uk

Different Strokes

9 Canon Harnett Court
Wolverton Mill
Milton Keynes MK12 5NF
Tel: 0845 130 7172
email: info@differentstrokes.co.uk
www.differentstrokes.co.uk/

Chest Heart and Stroke Scotland

Head Office
65 North Castle Street
Edinburgh EH2 3LT
Telephone: (0131) 225 6963
Fax: (0131) 220 6313
E-mail: admin@chss.org.uk
www.chss.org.uk/contact

INVOLVE

Promoting public involvement in NHS, public health & social care research

Wessex House
Upper Market Street
Eastleigh
Hampshire SO50 9FD
Telephone: 02380 651088
Textphone: 02380 626239
Fax: 02380 652 885
Email: admin@invo.org.uk
www.invo.org.uk

COREC (Central Office for Research Ethics Committees)

2nd Floor,
A Block,
50 Eastbourne Terrace,
London W2 6LX
email: queries@corec.org.uk
www.corec.org.uk

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(see also separate research governance documents for Scotland, Wales and Northern Ireland available via the Department of Health website)

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Hanley B. and Stanley K. *User and Carer Involvement: A good practice guide* Available from the Long Term Medical Conditions Alliance 202 Hatton Square, 16 Baldwins Gardens, London EC1N 7RJ

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Appendix: sample artefacts

This appendix includes examples of documents that have been modified to varying degrees to make them accessible to people who have stroke and aphasia. They are not to be reproduced as they are for demonstration purposes only. We hope you find them helpful.

The artefacts are reproduced with kind permission from the following people:

Artefact 1 Deborah Cairns (drawings Caroline Firenza)

Artefact 2 Kate Swinburn (drawings Caroline Firenza)

Artefact 3 Kate Swinburn (drawings Caroline Firenza)

Artefact 4 Deborah Cairns (drawings Caroline Firenza)

Artefact 5 Nina Fudge

Artefact 6 Nina Fudge

Artefact 7 Julie Hickin, Alison Greenwood, Jennie Grassly, Wendy Best

Artefact 8 Lawrence Erlbaum. Taken from Shewell C. and Patterson K. (1987) Speak and spell: Dissociations and word-class effects, in The Cognitive Neuropsychology of Language pp.273-294). M. Coltheart, G. Sartori & R. Job (Eds.), London: Lawrence Erlbaum Associates. Accessible version - Kate Swinburn

Artefact 9 Alan Hewitt

Artefact 10 Kate Swinburn (some drawings Caroline Firenza)

Artefact 11 David Howard, Gillian Porter and Kate Swinburn

Artefact 12 Kate Swinburn (drawings Caroline Firenza)

Artefact 13 Alan Hewitt

Artefact 14 Alan Hewitt

Artefact 15 Anna van der Gaag

Artefact 16 Anna van der Gaag

Artefact 1

Thinking for speaking

A research project on how people with aphasia express their thoughts

Information leaflet

Contents

Artefact 1

What is the purpose of the project?

After a stroke, some people have APHASIA.

This can mean they have trouble with **language**, **talking** and **writing**.

Some people have trouble getting their **thoughts out**.

They find it hard to **organise** their thoughts.

This makes it hard to express their **ideas**.

We want to find out what happens when you put your **thoughts** into **words**:

- What **processes** are involved?
- What makes it **hard**?
- What **helps**?
- What is it like **for you**?

This will help us to understand more about aphasia.

It may help us to design better **therapies** for people with aphasia.

The project will run from August 2002 to June 2004.

We are asking 10 people with aphasia to take part.

Do I have to take part?

No. It is up to you.

If you take part, we will ask you to sign a **consent form**.

You can **stop** at any time.

You don't have to give a reason.

This is OK. It will not affect any therapy you are having.

Artefact 1

What will happen, if I am interested?

(Researchers name) will meet you and talk to you about the project.

Not everyone has the right 'type' of aphasia for this project.
We will do a few **tests** to find out if you do.

(Name of researcher) will talk about this with you.

We also need to find out some details about your **stroke,** and about your **Speech and Language Therapy.**

We need to contact
your **GP**,
or your hospital **Consultant**,

and your **Speech and Language Therapist.**

Everything will be **confidential.**

If you decide to take part, (name of researcher) will arrange to see you again.

We will need **up to 10 sessions.**

They will be at times that suit you.

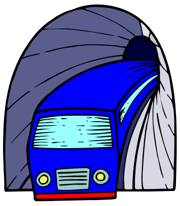
We can meet at Connect,

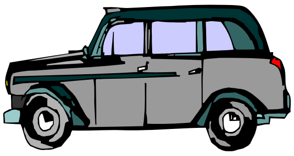
at your home,

or at **City University,**
whichever is best for you.

Artefact 1

We will pay any **travel costs**.





What do I have to do?

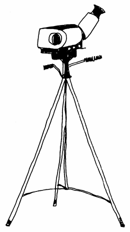
(Name of researcher) will do some **tests** with you.
She will talk with you about your **aphasia** and **what you think**.

Each meeting will last about **2 hours**.

They will go at **your pace**.

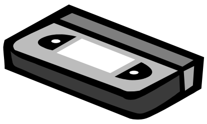
If you agree, the meetings

will be recorded on **video**.



We may watch sections of the video together, and talk about them.

The video



will not be shown to anyone else without your consent.

You can STOP or take a break at any time.

Artefact 1

What are the benefits?

The research will help us to understand more about aphasia.

It will tell us about how people **think** and **communicate.**

It will help us to understand how this **feels**.

It will tell us more about what **helps** you.

This will help us to design better **therapy** in the future.

What are the disadvantages?

This is NOT therapy… it won't help you to talk better.

We will need quite a lot of your time.

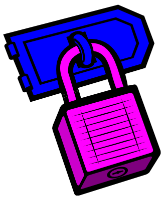
There will be up to 10 sessions.

What if I have a complaint?

You can talk to the project supervisor:

(contact details supplied)

Will everything be confidential?



Yes.

Everything will be kept in a **locked cupboard**.

Your name and address will not be used on any tests.

At the end of the project, we would like to keep the materials and videos.

We may use these for teaching or more research.

But if you want us to destroy the information about you, we will.

Artefact 1

What will happen to the research?

The results of the project will be written up.

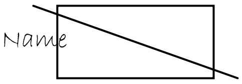
Parts of the project may be:

- Published
- Used in teaching or conferences

We will give you a summary of the results.

We will NOT use your name at any time,

unless you want us to.



Who is organising the project?

The project is supervised at **City University**.

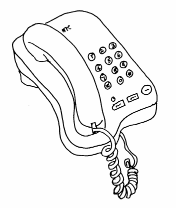
It is funded by **Connect**.

If you are interested:

… or if you have any questions,

please contact **(researcher's name).**

Telephone: 020 1234 5678



Name and address supplied

E-mail: supplied

Thank you very much
Name of researcher

Artefact 2

COMMUNICATION DISABILITY RATING SCALES PROJECT

INFORMATION SHEET

(Researcher's name supplied)
Speech and Language Therapist
(Contact address supplied)

Thus is a **project** about **how** your **talking problems affect your life**.

This is **NOT speech therapy.**

The project is looking at **how speech and language therapists look** at **talking difficulties.**

An **assessment** has been **written**.

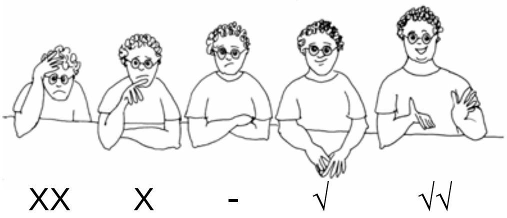
It asks **lots of questions**.

It looks at **how** your **talking gets in the way** of day to day life.

It has **questions** about **how you feel** about your talking difficulties.

You can **answer** the questions **by just pointing** if you want.

The tool is called a **Rating Scale.**



You will be **asked what you think** of the rating scales.

Your views are very **important**.

Your thoughts about it will help to **make the rating scales better**.

This will be the **first time** views of **people with aphasia** have **been included** in developing a tool.

If you would like to help – **here's what will happen**:

- **Researcher's name supplied** (a speech and language therapist) will **come and see you**
- She will **do the rating scales** with you

Artefact 2

Later on……**3 weeks later** you will come and **join other people** with aphasia.

- You will be **picked up** and **taken home** by **taxi.**
- The group will run at **City Dysphasic group, Goswell place**, by the angel tube.
- **(Name supplied)** (a different speech and language therapist) will **run the group**.
- **You** will **chat** about the rating scales.
- The group will take about **2 hours**.

If you **don't like it,** you can **stop**.

If you change your mind, you **don't have** to **come.**

No-one will **ask questions**. Your **speech therapy** will **not change** if you stop.

If you **want** to **take part**:

- **talk to** (name of **referring therapist**)
s/he will **make** all the **arrangements**

OR

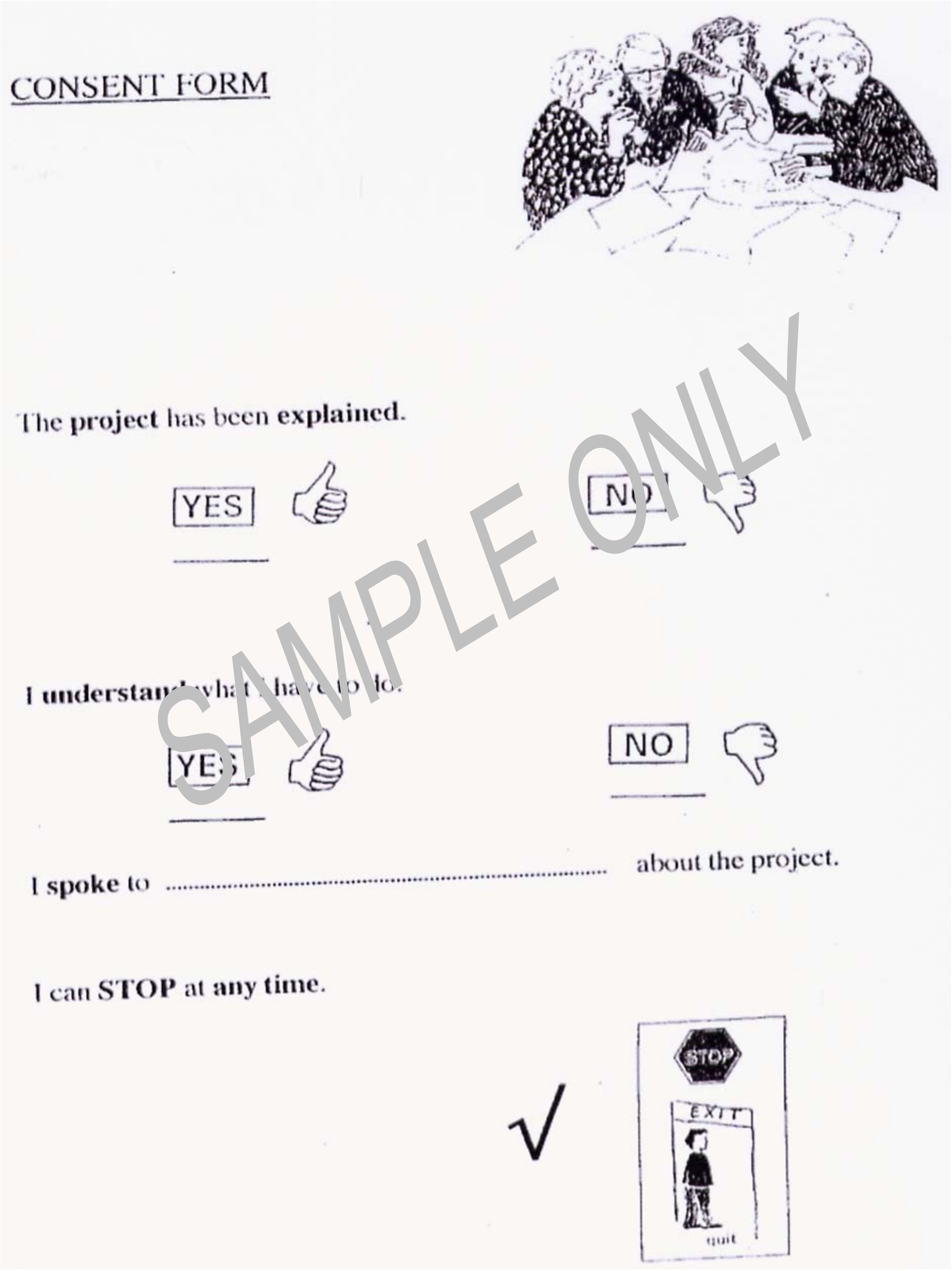
- **ring Researcher's name supplied** on **020-123-4567**
say 'I am phoning about the rating scales'

This project has been **looked at** by … **ethics committee**
(they **check** the project is **fair and good**).

They say it can **go ahead.**

THANK YOU….

Artefact 3



CONSENT FORM

The **project** has been **explained.**

YES 👍 ________ NO 👎 ________

I understand what I have to do.

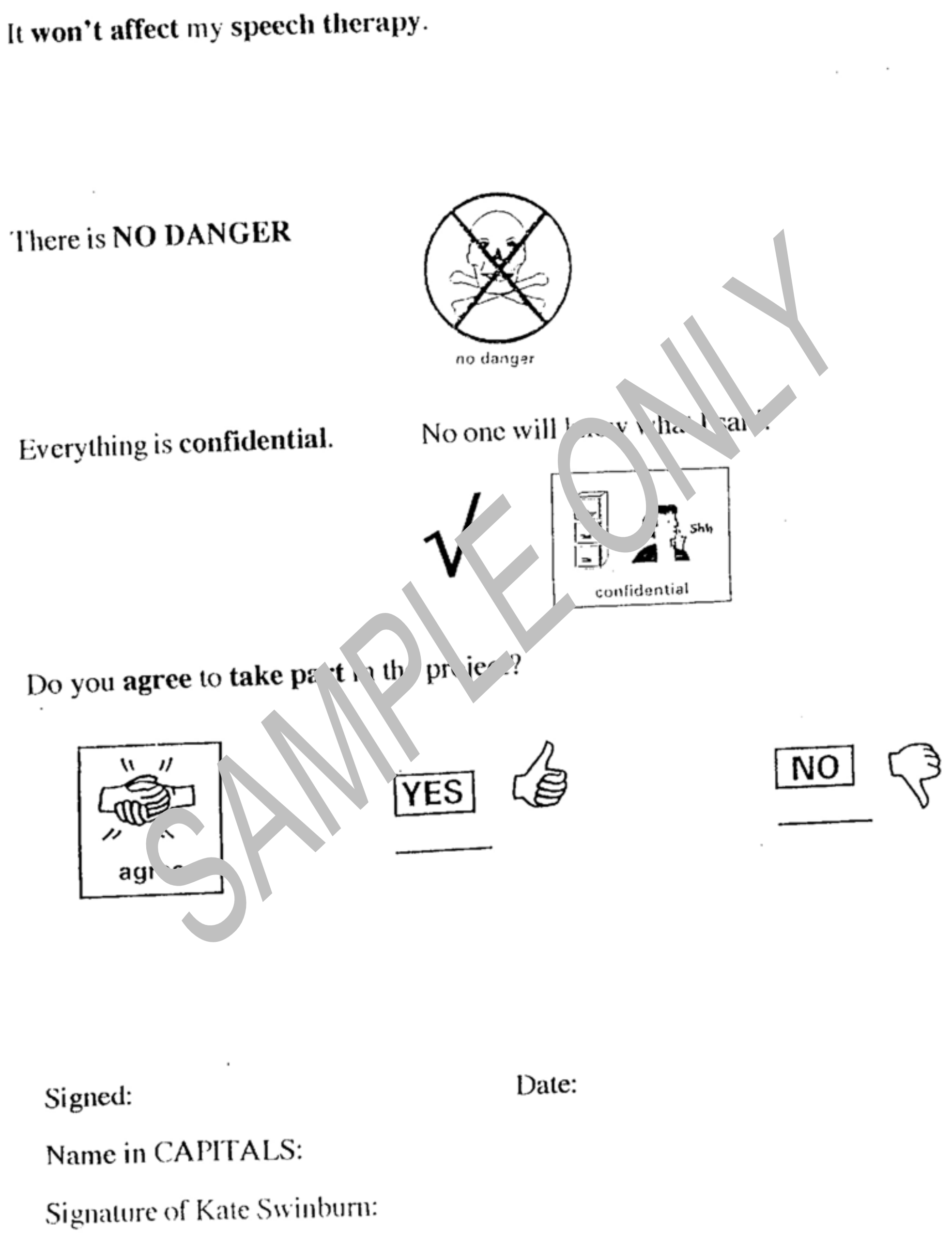
YES 👍 ________ NO 👎 ________

I spoke to .... about the project.

I can **STOP** at any time.

✓

Artefact 3



It **won't affect** my **speech therapy**.

There is **NO DANGER**

no danger

Everything is **confidential**.

No one will know what I say.

✓

Shh

confidential

Do you **agree** to **take part** in the project?

agree

YES ______

NO ______

Signed:

Date:

Name in CAPITALS:

Signature of Kate Swinburn:

Artefact 4

Consent form

Thinking for speaking research project

I have seen the information booklet about this project

☐ Yes ☐ No

I have talked with (researchers name supplied) about the project. She has answered my questions.

☐ Yes ☐ No

I understand what is involved

☐ Yes ☐ No

I know that I can stop at any time. This will not affect my therapy.

☐ Yes ☐ No

I agree to take part in the study. This is my free choice.

☐ Yes ☐ No

I am happy for the researchers to contact my GP, Consultant and Speech and Language Therapist for information.

☐ Yes ☐ No

Name: Date:

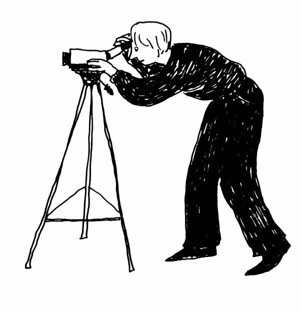
Signature:

Artefact 4

Video Consent form

Thinking for speaking research project

I agree to be recorded on video tape



☐ Yes ☐ No

I agree that the tapes may be used for teaching and research. My name will not be used.

☐ Yes ☐ No

Name:

Date:

Signature:

Artefact 5

Hospital name was supplied Research Ethics Committee

CONSENT FORM FOR PARTICIPATION IN RESEARCH PROJECTS & CLINICAL TRIALS

Title of Project: Enhancing patient/family participation in research and clinical service development: Evaluating the case of stroke.

Principal Investigator: Names were supplied **Other Investigators:** Names were supplied	**Ethics Committee** **Code No**: **Version No:** **Date:**

Outline explanation: You have agreed to take part in the Users Advisory Group for stroke research or stroke services. We are inviting you to take part in a study investigating the work of the Advisory Groups. The study aims to answer the following questions:

- ♦*how do people with stroke (and their family members) influence stroke research?*
- ♦*how do people affected by stroke participate in the development of stroke services?*
- ♦*does involving people affected by stroke change the quality of stroke research and services?*

A researcher based in the Department of (details were supplied), will investigate these questions in 2 ways: by observing the work of the Advisory Groups and taking notes about what happens in the groups' meetings; and by interviewing you and other members of the Advisory Groups about your involvement and your views of the Advisory Group's work and achievements. We would like to interview you twice to see if you experiences and views have changed over time. We would like to tape record the interview but if you prefer not to be recorded, the researcher will take notes instead. Interviews should take no more than 1 hour and will be arranged to suit you.

The researcher will treat anything you say – whether in Advisory Group meetings or interview -in strict confidence. Nothing you say will be attributable to you in any report that might be written.

You are free to decide whether or not to take part in the study. You can withdraw at any time. If you choose not to take part in the study, this will in no way affect any care you may be receiving. If you need any more information please ask the researcher.

I (name)____

of (address)

____

hereby consent to take part in the above investigation, the nature and purpose of which have been explained to me. Any questions I wished to ask have been answered to my satisfaction. I understand that I may withdraw from the investigation at any stage without necessarily giving a reason for doing so and that this will in no way affect the care I receive as a patient

SIGNED (Volunteer) ________________________ **Date** __________________

(Researcher) ___________________________ **Date** __________________

(Witness, where appropriate) ______________________ **Date** __________________

3 copies required:- one for researcher, one for patient/volunteer, one for patient's notes

Artefact 6

Involving people who have had strokes and their families in stroke research: an evaluation.

Can you help with a research project?

The research is being done at (Unit name given).

(Names supplied - emboldened) are the researchers working on the project.

(Three other names supplied – not bold) are also working on the project.

This **information book** tells you **about** the **research** and **how** you can **help**.

Please take time to **read** the following **information** carefully and **discuss** it **with others** if you wish.

Thank you for reading this.

Artefact 6

What is the research project about?

The **research** is **about** how to **involve people** who have had a stroke and their family members in **research**.

What helps people with stroke to take part in research?

What gets in the way?

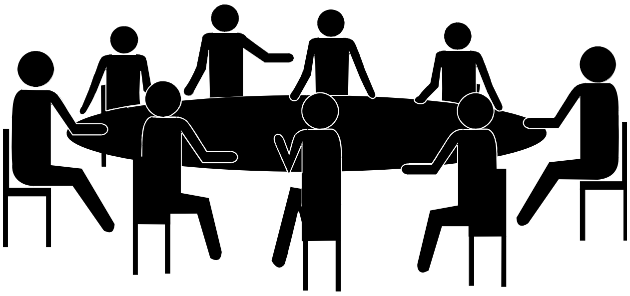
What helps family members of people with stroke to take part in research?
What gets in the way?

Does involving people who live with stroke improve the quality of research?

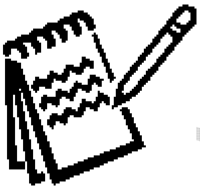
Artefact 6

What will the researchers do?

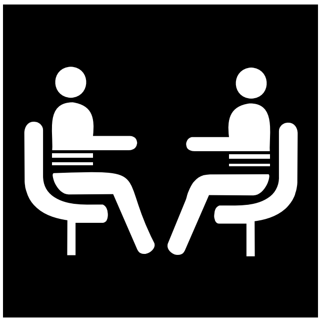
(**Researcher**) will **observe** what happens in the Stroke Research Team meetings.



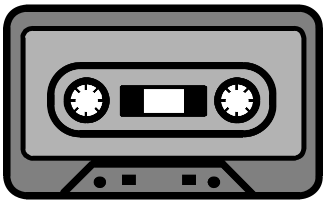
(**Researcher**) will **take notes** about what happens.



(**Researcher**) will **interview** people who have had a stroke, their family members and researchers to find out about their **experience** of being involved in stroke research.



(**Researcher**) will **record** the **interview** on an **audio tape**.
You can **stop** the interview at any time.
The **interviews** will last for about **one hour**.



Your **name** will **not** be **used**.

~~name~~

Everything you say will be **confidential**.

Artefact 6

Why is this research important?

The project will show researchers the **best ways** to **involve people** who have had a stroke in **research projects**.

The project will show how **people** who have had a stroke can **change** the way **research projects** are **done**.

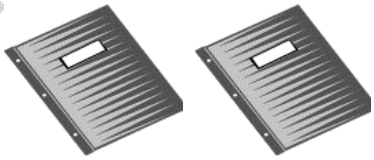
The project will **help researchers** who want to **involve people** who have had strokes in **research projects** in the **future**.

Artefact 6

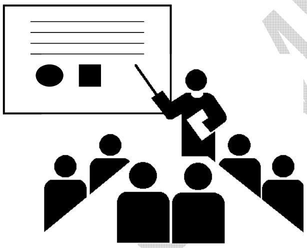
What will happen to the research?

A **summary** of the **results** will be **sent** to **you**

The **research** will be **published** in **reports**.



The **research** will be used for **teaching** or at **conferences**.



The **results** will help **future** researchers **develop ways** of **involving people** who live with stroke in **research projects**.

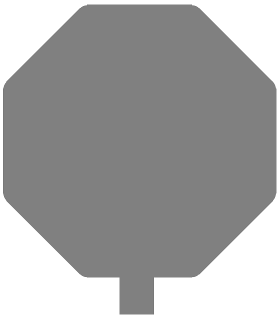
Artefact 6

? Do you have to take part?

- You are **free** to decide whether or not to **take part** in the research.

- If you **agree** to take part you need to **answer** some **questions** and **sign** the **consent form**.

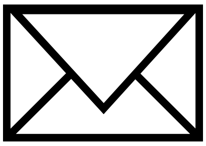
- You are **free** to **stop** the **research** at anytime and you do not have to give a reason why.



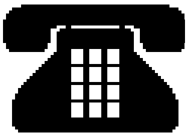
Artefact 6

Any questions?

If you have any questions talk to **NAME GIVEN**



(Name and address supplied)



(Telephone number supplied)

(email supplied)

Artefact 6

Consent Form

Involving people who have had strokes and their families in research: an evaluation

👍	Yes ☐	No ☐
I have seen the information book about the research		
I have talked with (name supplied) about the research	Yes ☐	No ☐
(Name supplied) has answered my questions	Yes ☐	No ☐
I understand what is involved	Yes ☐	No ☐

Observation of research meetings

	👍	👎
I understand that (name supplied) will come to meetings, watch what happens and take notes.	Yes ☐	No ☐
I understand that my name will not be used.	Yes ☐	No ☐

Artefact 6

Interviews

	👍	👎
I agree to be interviewed	Yes ☐	No ☐
I agree to be recorded on audio tape	Yes ☐	No ☐
I understand that I can stop the interview	Yes ☐	No ☐
I understand that my name will not be used	Yes ☐	No ☐

If you agree to take part in this research please could you sign below:

Name ……………………………………………………………..

Signed (volunteer)………………………………. Date …………..

Witness (where appropriate)………………………… Date …………..

Signed (researcher)…………………………….. Date …………..

Artefact 7

A CLINICAL INVESTIGATION OF THE TREATMENT OF WORD FINDING DIFFICULTIES IN APHASIA USING SOUND AND WRITTEN CUES

- A research project.
- Looking at: “How helpful is Speech and Language Therapy for word finding problems?”

The Research Project:

- Will help us to answer questions about aphasia

? ?

? APHASIA ?

? ?

- You may find that the therapy does not help you.

Taking part in the research project means:

- I will ask you to tape record conversations with someone who you talk to a lot.

- You can choose this person yourself.

Taking part in the research project means:

- Seeing me once a week for about 9 months - 1 year.

- For the first two months I would do some tests of your language skills and ask you about the difficulties you have in daily life

Taking part in the research project means:

- Next I would give you a naming test.
- After this I would start therapy.
- I would meet you once a week to practise saying words by naming pictures.

- If you get stuck on a word then I would give you help.
- This treatment would last for 8 weeks.

Taking part in the research project means:

- I would then do the naming test again and tape record some more conversations.
- Next I would meet you once a week to practise the same words using everyday situations.

- This would last for 8 weeks**.**

Artefact 7

Taking part in the research project means:

- Afterwards, I would do the naming test again.
- I would also tape record some more conversations.

- After another 2 months I would repeat the naming test and conversations.

Taking part in the research project means:

- None of the studies should be uncomfortable or embarrassing.
- But you won’t be able to have any other Speech and Language therapy while you are doing the research.

Taking part in the research project means:

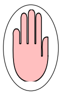
- The results of the study may be described in research papers or in talks.

- You will be kept anonymous.
- We will store the audio-tapes as confidential records.

Taking part in the research project means:

- You do not have to take part in this study if you do not want to.

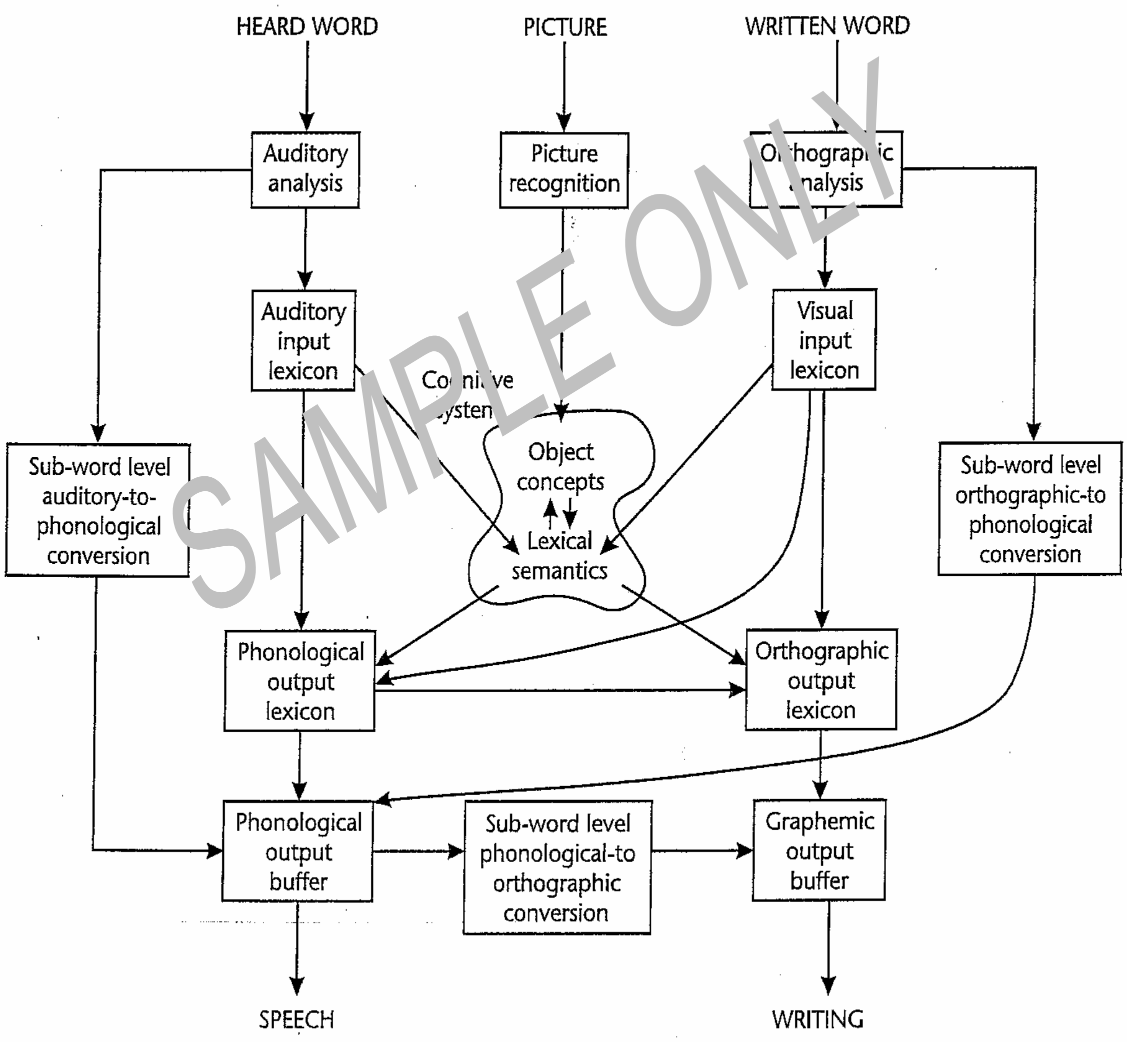
- If you decide to take part you may withdraw at any time without having to give a reason.



This research proposal was reviewed by the Joint UCL/UCLH Committees on the Ethics of Human Research, and Wycombe NHS Primary Care Trust Local Ethics Committee.

Artefact 8

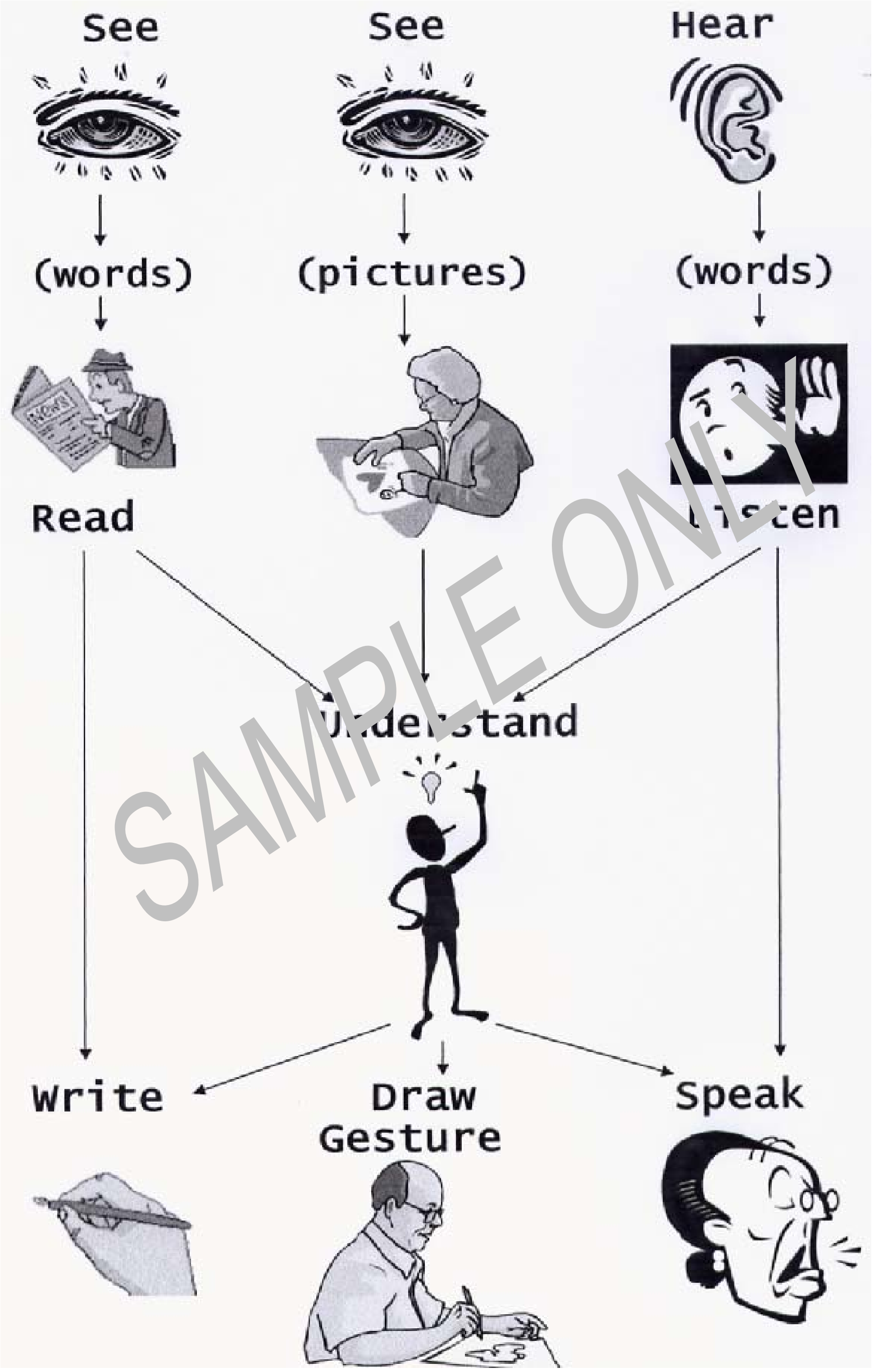
Theoretical model of language processing (in a less accessible form)



The components of lexical processing (based on Shewell & Patterson, 1987).

Artefact 8

Theoretical model of language processing (in a more accessible form)



Artefact 9

To all members of the

Way in

Aphasia Advisory Group

19 January 2005

Thank you for **agreeing** to take part in the Way in **Aphasia Advisory Group**.

The Way in is a **"Communication Access"** **project** to provide **people with aphasia** and **stroke service providers** the conditions to **take part** in

- meetings
- document preparation
- conversations
- processes

through a **toolkit - a training resource**.

The first **introductory** meeting of the Way in **Aphasia Advisory Group** is held at **11.00am-3.00pm** on **Wednesday 26th January 2005** *at Connect*

We hope to see you there

Connect will pay **all your expenses**

With best wishes

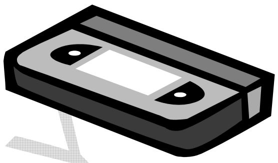
Name and photo Supplied

Working Together Co-ordinator

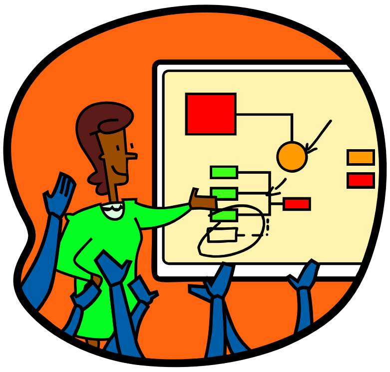
Artefact 10

Information Sheet
Video about self advocacy group experiences

Aim: to get SOUND BITES of YOUR **experience** of HEALTH CARE



- GOOD experiences of health care
- BAD experiences of health care
- ideas to make things BETTER



We want people with aphasia to contribute to the COURSES that
we run at CONNECT.

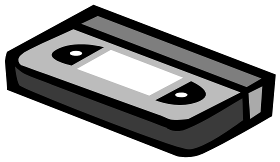
ONE WAY is to use video CLIPS.

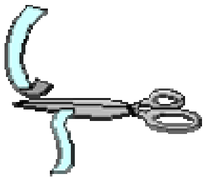
Audience for the courses:

- speech and language therapists
- health workers (nurses, therapists)
- social care (support workers, volunteers)

Length

I will video for a lot of the session.





I hope to cut this to several 2-3 minute clips.

Artefact 10

What made HOSPITAL GOOD for you?

✓

What made HOSPITAL BAD for you?

✗

Artefact 10

What made a GOOD doctor/nurse?

✓

What made a BAD doctor/nurse?

✗

Artefact 10

WHY was your THERAPIST good?

√

WHY was your THERAPIST bad?

X

What could **PEOPLE**

have done to make things

BETTER for you?

Artefact 10

If **YOU** had ALL the **HEALTH SERVICE MONEY** for stroke,

How would YOU SPEND it?

How would you DESIGN a hospital to SUIT **people** who have had a **stroke**?

Artefact 11

Rating scales taken from a standardised tool (less accessible and acceptable)

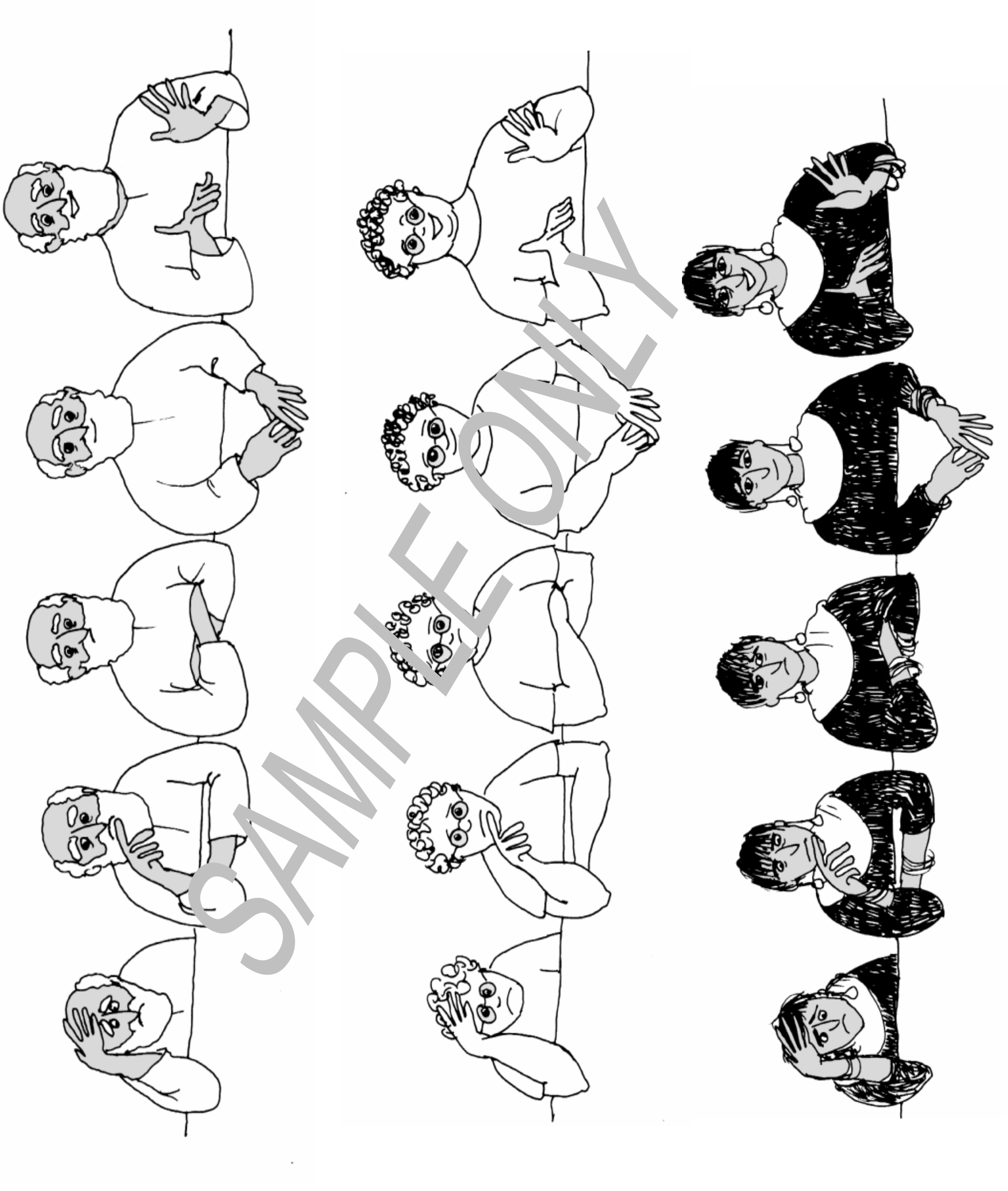
Impossible	Very difficult	Difficult	OK	No problem

4 <-------------> 3 <-------------> 2 <-------------> 1 <------------> 0

X √

Artefact 11

Modified rating scales (more accessible and acceptable) - three versions depicted



Artefact 12

Getting involved in stroke research
Be an expert in aphasia

Here are some questions you might want to ask…

<u>The project</u>

What are the **aims** of the project?

How **long** will the project last?

Who's in **charge**?

What do I have to do?

How will the **information** I give, be **used**?

Will I be **paid**?

How will **other people with aphasia** know about the project and its **results**?

What happens to the **information after** the **project**?

<u>Meetings – interviews</u>

What do I **have to do?**

Where will meetings be held?

Who's in the **group**?

How often will we meet?

How **long** will each meeting be?

Artefact 12

My needs

How will my **specific needs** be met?

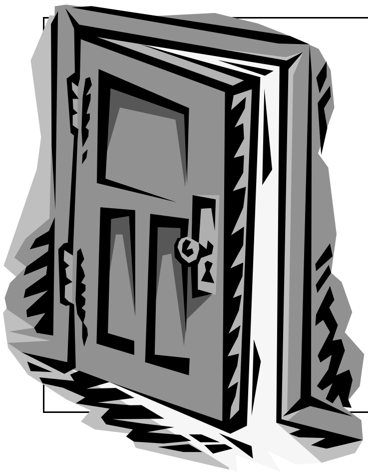
- **how** will I **get to the meetings?**

- will the **talking** be **too quick** for me?
- will some-one **scribe** for me?
- how will you **check** that **I am included** in the **meeting**?
- will there be **paperwork** at the meeting?
- will there be paperwork **before** and **after** meeting?

Do you have any **other questions**?....

?

Artefact 13



Way In

Ground rules

- Be **concise** and to the point
- Be **clear**
- Be **honest**
- **One person** speaks at a time
- **Listen to** and **be respectful** of others in the group
- Try and fix **convenient dates** for meetings well in advance
- If more than one person **can't attend a meeting** find **another date**
- If you miss a meeting **take responsibility** for finding out what happened

Artefact 14

Agenda

Way In **Aphasia Advisory Group meeting**

from **10.45am** *to* **3.00pm**

Tuesday 1st March 2005

- 10.45 – 11.15am *Coffee*

- 11.15 –11.30am **Recap** and **up-date** on project
- 11.30am – 12.30pm **Review** of Aphasia Advisory Group experiences - **keeping track** of your **involvement**

12.30-1.30pm **Lunch**

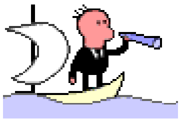
- 1.30 – 2.15pm **Keeping track** of **involvement** - **plans** and **projects**
- 2.15 - 3.00pm - “ What is a **toolkit**?”
  Looking at and thinking about **teaching**

Artefact 15

The Connect Evaluation Project

Minutes of Debriefing meeting

Held on 23 January 2002



Present:

R (person with aphasia)	S (person with aphasia)	L (person with aphasia)
A (researcher)	R (researcher)	S (researcher)

(names appear in full in original document)

Apologies: J

1. Introduction

A(researcher) introduced the **purpose** of the **meeting**.

a. To **listen** to the **R, R and L'**s (all people with aphasia) views of the **Meeting** held on 30 **October 2001**.

b. To discuss what might be the **best way** of **organising** the **next meeting**.

2. Views on the last meeting

Individual members made the following **comments:**

The **Introductions** at the **beginning** of the **meeting** were **not helpful.**

It would have been **more helpful** to have a **written summary** of who **each member** of the group was **before** the **meeting.**

It would be useful to have **digital photographs** of all the **members** of the group included in **future minutes.**

The **advisors** felt that they were **pleased** to have been at the **meeting**.

The **purpose** of the meeting was to **find out where** the **evaluation** was **going.**

Some of the **discussion** was **too technical to** follow and it was **difficult** to **contribute.**

In some ways, the **discussions** were **'held back'** because of the **different** kinds of **knowledge and experience** that the different members had.

The **minutes** were a very **helpful** way of setting out all the **issues.**

3. Future meetings

A (researcher) proposed that **future meetings might** be made up of **two parts;**

Part 1: A meeting to discuss the **progress** of the **project, attended** by **all advisors.**

Part 2: A technical meeting**,** attended by the **scientific advisors.** This would allow all the advisors time to give their expert views to the Research Team**.**

What we agreed:

It was agreed that we would:

- Have a **Pre-Steering Group meeting two weeks before** the **Steering Group meeting.**

The next **Steering Group** meeting would

- Be **divided** into **two parts;**

Part 1:

The **Research Team** would **report** on the **progress** of the **project.**

The **Research Team** would give a **summary** of the
Pre- Steering Group meeting.

The **advisors with aphasia** would make **comments** on this **summary** to the **all** the **members.**

Part 2: The **technical group** then would meet to **discuss scientific issues separately.**

4. Date of Next Meeting

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The **date of the next Pre- Steering Group** would be the **12 June 2002**

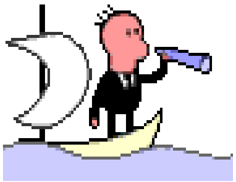
The date of the next **Steering Group** meeting had been **changed** to **2 July 2002**.

Artefact 16

A STUDY OF CONNECT THERAPY AND SUPPORT SERVICES

A
SUMMARY

FOR
PEOPLE WITH APHASIA
AND THEIR RELATIVES



'The Discovery Project'

Artefact 16

What is Connect?

Connect is a **national charity** providing **therapy and support services** to **people with aphasia** and their **families**. It is based in **London**.

Who carried out this study?

An independent team of **researchers** from the **University of Strathclyde** in **Glasgow**.

The team:

Dr A (full name supplied), a **speech and language therapist**

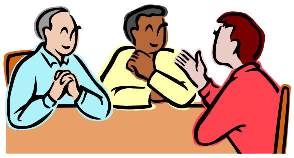
Dr S (full name supplied), a **statistician**

C (full name supplied), an **expert** on **voluntary organisations**

S (full name supplied), an **experimental researcher**

B (full name supplied), a **qualitative researcher**

Who took part?



People with aphasia and **their relatives** who were:

- **new** to Connect

- coming for therapy at **Connect during 2002/3**.

Artefact 16

Why did we do this research?

To find out..

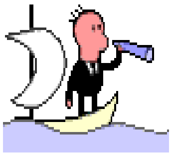
- What **people with aphasia** and their **carers** thought about **Connect**
- To discover if there were any **changes** in their **quality of life** and **communication** after coming to **Connect** for **six months**.

How did we do this?

We interviewed people…

- **Before** they came to **Connect**
- ***After 6 months*** *at* ***Connect***

They also completed **assessments** of **quality of life** and **communication before** they came to **Connect** and **after 6 months** at **Connect.**



Artefact 16

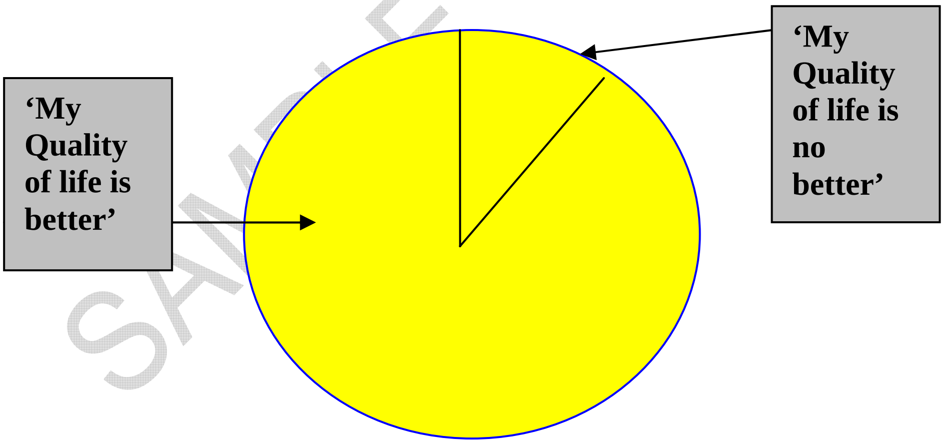
What did we discover?

Most people who came were **positive** about **Connect**.

Most people who came said their **quality of life** had **improved since** coming to **Connect**. They told us:

- They were **going out more** often
- They were **more sociable**
- They felt **more confident**
- They **felt better** about **themselves**
- They **enjoyed** the **groups** at **Connect**

These people all **improved** on the **quality of life assessments** as well.



What people told us about their quality of life since coming to Connect

A small number of people **told us** their **quality of life** had **not changed**.

They told us:

- Their **lives** had **not changed** since **coming to Connect**
- They did **not like being with** other **people** who had similar experience of **stroke** and **aphasia**
- They did **not like** having **therapy** in **groups**

These people **did not improve** on the **quality of life** assessments, but most **did improve** on the **communication** assessments.

What did people say about communication?

Most people told us their **communication** had **improved**.

85% of **people with aphasia** said their **communication** had **improved since** coming to **Connect**.

93% of **relatives/carers** said their **partner's communication** had **improved since** coming to **Connect**.

They told us:

- They felt **more confident** about **communicating**
- They were **using other ways** of **communicating** as well as speaking
- They felt they were **getting their message across more often** than before

These people showed **improvement** on the **communication assessments** as well.

Artefact 16

What next?

The results of this **study** will be **used** in **different** ways, for example:

- To help **Connect improve** its **services**
- To allow **other professionals** to **learn** about **Connect's services**
- To help other **researchers** to **find out more** about **aphasia**

THANK YOU!

The research team would like to thank all the people with aphasia, their relatives and carers who took part in this study.

If you would like to **find out more** about this study, **please contact:**

Name, address, telephone number and email supplied