The ACT NoW Study- Involving Service Users in Research.

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This document has been written for the UK Stroke Research Network and is intended to be a guide for individuals who are intending to involve service users in research. It offers advice on practical issues in setting up a user group, as well as addressing the underlying principles which must be considered before it is established. It has been written by the facilitators of the ‘Assessing the effectiveness of Communication Therapy in the North West’ (ACT NoW) Research User Group (RUG): a qualified speech and language therapist, and members of the research team, through direct consultation with the RUG.

The ACT NoW study is a pragmatic, multi-centred, randomised controlled trial, designed to evaluate the effectiveness, cost-effectiveness and service user preferences for communication therapy following stroke. It involves a comparison of highly structured, intensive speech and language therapy intervention for people with aphasia, and/or dysarthria, following stroke with direct contact that is not communication therapy (attention control). Service users will participate in all stages of the design and implementation of the trial to ensure that the evidence is relevant to the needs of decision makers and the target population.

Traditionally people with communication difficulties following stroke have been excluded from research, because of perceived barriers in communication. These include impairments of motor speech production (dysarthria), and/or of language skills (aphasia). People with aphasia may have difficulty in understanding or expressing the spoken or written word, and therefore, are often not included in studies. However, it is possible to be more inclusive. The ACT NoW study sought the advice of a RUG in how to overcome these communication difficulties.

There are between 8 and 10 members in the ACT NoW RUG, all who have aphasia and/or dysarthria following stroke. Additionally, there are also two carers in the group. Members vary in age, background, severity and type of current communication difficulties. They are facilitated by individuals who are experienced in group work and ensure aphasia-friendly communication throughout.

This document is written from the perspective of involving service users with communication difficulties following stroke, with many of the practical problems discussed relevant to this. However, the underlying principles may be generalisable to researchers aiming to involve clients other than those with aphasia and/or dysarthria. The issues covered have been divided into four main topics, each exploring a different aspect of recruiting for, and utilising, a research user group:

1) The values in seeking the involvement of service users
2) The environment in which service users will meet and be encouraged to participate
3) Materials to attract service users to become involved in research
4) The specific role of the ACT NoW RUG

(1) Values in seeking the involvement of service users

It is important to be clear and transparent about the values and principles that are driving user involvement:

(i) Benefits to be gained from seeking the involvement of service users
(ii) The principles underpinning user involvement

Benefits to be gained from seeking the involvement of service users

- Intending to carry out research ‘with people’ rather than research ‘done to people’ will contribute to the validity of our work. This essentially is an issue of power. Researchers must seek to redress the balance of power and involve the perspectives, experiences and knowledge of those whom the research is about.

- Through research it is possible to make significant improvements in the social role and political status of those users involved. At its most basic this is about voices being heard and people becoming visible. At its most radical it is about challenging socio-economic and political structures that serve to contain people’s potential.

- Users have knowledge, and their knowledge is of value and significance. Many groups over time have been written out of historical and social discourse. Some varieties and origins of knowledge are considered more valuable than others. Service user involvement in research both challenges these ideas, and can lead to the production of new knowledge.

The principles underpinning user involvement

- The researchers who facilitate involvement hold positions of power. They can seek to redress this balance of power through:
  - the open acknowledgement of the power imbalance within the group and it’s likely effects (simply trying to let it not matter, or trying to ignore it will not address the problem);
  - working actively to give up that power in ways that are incremental and responsible (saying you won’t lead, or won’t make the decision is not giving up power. Firstly, others have to be empowered to take on those roles);
  - being alert to when power imbalances get in the way of the group process (not using your greater knowledge or resources of
• Seeking to empower service users. It is important to realise that empowerment is not something that can be given, but something that has to be taken. Those who are facilitating involvement have a responsibility to create the conditions in which that empowerment can occur e.g. if the context is aphasia-friendly, respectful and open, then people with communication difficulties will feel empowered to contribute.

• Promoting partnership. This value is allied to the two previous, but is important in driving decision making. There is a distinction between facilitators deciding what a group might do and then being supportive to enable it; and facilitators working in partnership with the group to make decisions about what they should become engaged in. It is not always possible for service users to be partners at every stage of a research process, but being upfront about this, and the reasons why not, are important.

• Respect. Basic respect for individuality and diversity is crucial to any work with service users.

• Confidentiality. This is important to group process and also to building group identity. It is not always straightforward to implement.

• Equality. This is one of the basic terms of engagement in service user/service provider involvement. It is also an active process that has to be constantly strived for (through many of the issues discussed above).

(2) The environment in which service users will meet and be encouraged to participate

Putting these values into practice means giving consideration to the barriers presented by the environment, which could prevent engagement. There are changes which can support people to attend, and to engage in the meetings. Many of these adjustments may appear trivial; however they are all part of the bigger picture. Putting these values into practice requires that attention is given to fine detail. What may seem a small issue to a researcher can seem an insurmountable barrier to someone else.

In the ACT NoW study the service users are people who have aphasia and/ or dysarthria; however, they may also have other associated difficulties. Aphasia is, broadly defined, a language problem, but it is an umbrella term for a range of difficulties which are different for each person. It is necessary to make sure that arrangements are made to take into account the varying needs of all participants. If
possible, ask users themselves what will help and what will make things more difficult.

Consideration can be given to potential barriers in the following categories and some suggestions have been made. The list is not exhaustive, but is intended as a guideline to support considerations.

- Venue and transport
  - Choose the meeting place with consideration for the service users first, not the easiest or cheapest option for the staff.
  - Find an accessible meeting place which will include easy access for different forms of transport.
  - Look for bus and rail links with taxi services immediately outside.
  - Make sure there is easy car parking outside the venue with enough disabled spaces.
  - There should be level access or easy lift access.
  - The meeting room must be near to the door to prevent a long walk.
  - Wheelchair loan should be available if required.
  - There should be disabled toilets within close proximity.
  - Offer to arrange transport support. Travelling can be difficult for people who have aphasia as they may find it more difficult to ask for help. It is essential to support travel.
  - If taxi transport has been arranged, provide a printed card for the driver with directions and details of payment.
  - Give information on travelling expenses in advance as handling money can be difficult for someone who has aphasia.
  - Information about the venue and room should be given in advance of the meeting (in an accessible form) to encourage attendance. People with aphasia may find it hard to use maps or follow long directions. Give directions in a way that is easy to understand (e.g. - the hall is next to a park with green railings).
  - Signs for the meeting should be available from the transport links using visually recognisable signs (e.g. logo for the study or the research institution).
  - There must be someone at the entrance to meet and greet, and help with any mobility difficulties. Scan a photo of this person onto the letter of invitation with their name. The greeter should wear a large name badge with their first name in sentence case letters in an easily-read font such as Arial or Comic Sans.
Room

- The room must have the right ambience, it must feel comfortable and welcoming, large enough for the number of people attending but not too large.
- Arrange the room furniture to facilitate the involvement. People who have aphasia may choose to write or draw their responses so make sure there are firm central tables for everyone to use. The tables need to be the right height to accommodate a wheelchair.
- Make sure that the room is the right temperature for the season.
- The lighting should be good for reading and writing etc at the table.
- Have refreshments available in an adjacent area or in the room itself. Offer a range of refreshments to suit all tastes. Many people who have aphasia will have had a stroke. Bear in mind the physical difficulties for using a china cup and saucer and the potential for harmful spills.
- It is essential that the room is quiet. People who have aphasia can find it very difficult to screen out background noise and concentrate on the conversation in the room. A busy corridor, engine noise from cars outside, a noisy fan or telephone ringing in an adjacent room can prevent someone who has aphasia from concentrating.
- Make sure that there is space for a flip chart to be positioned in a way that everyone can see and that there is space for the use of a projector and screen if appropriate.
- Research staff should, where possible sit amongst the meeting participants.

Ground rules

It can be useful to share some ground rules and agree them at the start of the meeting. This will allow for greater involvement of all the people present. The ground rules apply to anyone who is in the meeting room. This is particularly important for people who have aphasia as the ‘normal’ style of meeting communication would prevent involvement. The agreed group rules at ACT NoW RUG meetings are shown in appendix 1.

Rules may include the use of cards to support engagement in the meeting. People who have aphasia can find it difficult to interrupt and to produce a response on cue. Meeting cards can be a useful way to overcome this. The cards used for this project include words with accompanying pictures to represent:

- I have something to say
- Stop, I need a break
- You are going on too long
- I don’t understand

Aphasia can make it hard to remember names. All people present in the meeting should wear a name badge. This should have the preferred name of each person printed in large letters (e.g. font 72) on badges that are easy to pin on (safety pins...
are difficult to use with one hand, the expensive magnetic badges are the easiest). Introducing staff as ‘professor’ or ‘doctor’ can create a power imbalance.

**Timing and pacing**

- The meeting must be structured to allow for lots of breaks, at least one per hour. Encourage a system that allows the participants to ask for breaks when they want them as well as the planned breaks, but in addition be alert for signs of fatigue.
- Give information at the start about the structure of the meeting, with information about asking for extra breaks.
- Allow plenty of time for introductions and welcome.
- Do not rush the pace of the meeting. Allow time for each discussion point. Using different ways to communicate e.g. drawing or writing can take more time. Allow for this time. Also allow time for recap of discussions and clarification.

**Support materials**

- People who have aphasia may need to use support materials to help them engage in the conversation. These can provide support both for understanding the discussion and for expressing ideas and opinions.
- There are some basic materials that should always be available. These include:
  - Easy-write pens and paper
  - Alphabet charts in both upper and lower case
  - Number charts

Other resources such as Argos catalogues, holiday brochures, an atlas or maps can be useful.

In addition there may be other resources that are relevant to the specific topic e.g. pictures of hospital procedures, pictures of emotions. These may be bought commercially or replaced/supplemented by those more readily available (for instance clip art or software packages such Boardmaker™). It is important not to be too selective about the resources surrounding the topic. The conversation may flow in an unexpected direction, so keep them broad, and be inventive with a pen and paper if the materials are not readily to hand.

Using materials to support conversation with people who have aphasia takes practice. Access some training and arrange an opportunity to practice this skill before the meeting. This technique should not be regarded as a last resort for if things go wrong. It should be an integral part of all the communication.

These features are the scaffolding around the role description. They enable someone to make a judgement about whether they might be able to ‘cope’ in the role and whether the tasks are feasible for them.
(3) Materials to attract service users to become involved in research

All written information needs to be accessible for people who have aphasia. It is important that this is seen as an integral part of the process, and not as an add on. It should include letters of invitation, maps and directions, signposting, agenda (sent in advance), meeting plans, items for discussion, overview of discussion points, expense forms etc.

Materials should be written from the outset in ways that are accessible to members of the group. This is more effective than translating our ideas once written down into what we think might make sense. It is advisable to use different ways of contacting potential members, to encourage a broad spectrum of people. Below are two potential ways to access members.

- A letter for the speech therapists of appropriate individuals, to be read to the patient during visits (appendix 2)
- A letter to be sent to individual clients, inviting them to the meeting, and providing specific details to facilitate their arrival (appendix 3)

(4) The specific role of the research user group

It is very helpful whilst encouraging people to participate, to initially be clear about ‘jobs’ to be done, rather than more vague goals such as support or advice. Making the role concrete at first makes it less unknown and less anxiety-provoking. With experience and confidence, it then becomes easier for members to contemplate less bounded and more general roles such as ‘advice-giving’ or ‘dissemination’.

The following is based specifically on our experience of the ACT NoW RUG work. We contrast the professional language of this document with some of the actual terms and approaches we used in practice to begin to give a feel of the kinds of adjustments one might have to make in working alongside a group such as the ACT NoW RUG.

Role - based on the feasibility study tasks

To assist with the ACT NoW research project [in reality we always used the word ‘work’ even though it was not traditionally paid work. This made it clear there were jobs to be done and it was not just ‘talking shop.’ Also it proved very important to group members’ self esteem. We rarely used ACT NoW as it was a very difficult acronym to remember and seemed an unnecessary impediment to understanding. We tended to say the ‘university research’].
To participate in the design of accessible information and recruitment materials for people with aphasia/dysarthria [this tended to get expressed as ‘help people with stroke understand’, and ‘help people decide if they want to be in the research’].

To be prepared to use your personal experience of stroke and communication difficulties to advise the research project. [this was presented in terms of emphasising why potential user group members were being targeted in the first place – it may not be as obvious as we think].

To assist in the design of appropriate and sensitive ways to interview people who have communication difficulties following a stroke [we found it helpful to ask ‘how do we help people to tell us their feelings and ideas’].

To help with the training of research staff [in reality we talked about ‘giving feedback’ and helping research staff to ‘communicate better’ – these were more concrete than ‘training’].

To support public awareness of the project [this was often difficult to get across because it was easy to understand the idea of raising public awareness of stroke, but it was harder to understand the significance of raising public awareness of a specific research project. It was only with time and with increasing group identity that the significance of the ACT NoW project itself became stronger].

To assist in the dissemination of the research findings [words like ‘dissemination’ were of little use. They became replaced with ‘tell people about what is going on’, ‘talk about what you do in the project’].

Conclusion

The ACT NoW RUG has provided valuable input on specific tasks during the trial. The group were active participants in the development of recruitment and consent materials, qualitative interviewing materials, recruitment of research staff and public dissemination. Their success has been partly due to the expertise and commitment of the research team in allowing the RUG to make a valuable contribution.

For anyone with a chronic illness or disability who is thinking of participating in research, considerations of practicalities of the role, not just what the role might be are important. These will affect who will join the research, and if addressed should allow for a varied range of people to be included. Our intentions and values in encouraging user involvement are also important as these affect our practice and the quality of the work we produce with service users. Ultimately, it is best to look at the role of service users and researchers developing into a partnership. If these factors are taken into consideration they will help contribute to the validity of our research work.
Appendices

Appendix 1 – ACT NoW RUG group rules

Appendix 2 – A letter for speech therapists to give to potential service user group members

Appendix 3 – An invitation to a user group meeting to send to potential service users
Appendix 1 – ACT NoW RUG group rules

Group Rules

- Everyone is equal

- Take turns

- No interruptions, give each person time

- No one to hog the limelight

- All forms of communication are accepted

- Members show respect and support

- All decisions are written down

- All decisions are taken in the meetings

- Fun is allowed

- Everything is confidential

- Anyone can drop out at any time
Appendix 2 – A letter for speech therapists to read to potential service user group members

We would like you to think about taking part in running a research project.

Why Me?

We feel that you have valuable experience. We want you to tell us your opinions.

What is the research project?

This project compares two different ways of giving people help with their communication when they have had a stroke.

Who is doing the project?

The project is organised by people from Manchester University with help from experts who know a lot about stroke and communication problems.

Who else is in this group?

There will be about 10 people. Most of these people will have communication problems after a stroke. There will also be some carers whose partners have communication problems after a stroke. Each person has been asked to be in the group because they have valued opinions.

What are the good things and bad things for taking part?

Good things
- Your opinion may make a difference to the way help is given in the future
- You may develop new skills as part of being involved
- Your confidence may grow as part of being involved
- You may meet some interesting people

Bad things
- You will need to spend some time coming to the meetings
- You will not be getting extra therapy for your own communication difficulties
- You will not immediately be able to change the way speech and language therapy is given.
What will I have to do?

We will ask you to come to several meetings. We want to hear your opinion about speech and language therapy after a stroke. We will need your help to design some information for people who will be taking part in the research.

Where will the meetings be held?

The meetings will be held in Lostock Parish Centre in Bolton. This building is easy to find. It is easy to park just by the door. We will send you a map.

How many meetings will there be?

We will meet first on 14th July 2004. The first meeting will be to get to know each other. We will also be able to make sure that you have the right sort of help to communicate well in the group. We are not sure exactly how many meetings there will be. There may be 1 meeting a month from September.

How long will they last?

The first meeting will last 3 hours. It will start at 12.00. There will be breaks for refreshments. At the first meeting we will agree what time of day is most suitable for everyone. We will also decide what day of the week is best.

Will I understand what is happening?

We will tell you what you need to know using plain English. We will also help you to understand by using pictures, photographs, writing, gesture and other ways of communicating.

How will I be able to contribute?

We will help you to get your ideas across. You can use speech, pictures, writing and other ways. We will give you lots of help to make sure that you can express your ideas.

What will happen if I can not come to a meeting?

We hope that you will be able to come to most meetings. We will plan the meetings so that they are at a convenient time for most people. We understand that there may be some that you can not come to.

Will I get help with transport and any other arrangements?

If you need help arranging transport to the meetings then we can help you. We will pay your travelling expenses. If you have other arrangements to make, or any other expenses, we will help.
Can I bring someone with me?

You can bring someone with you if you do not want to travel alone. We would like you to come into the meetings on your own.

Will I get paid?

You will get a small amount of money. This is because your opinions are valuable.

……………………… (Signature)
Speech and Language therapist
Dear

We are ready to start the meetings about the research in therapy for aphasia.

We would like you to come to a meeting on

- Wednesday 22\textsuperscript{nd} September 2004
- at Lostock Parish Centre
- Tempest Road, Bolton
- in the 'Meeting Room'
- starting at 1 pm and finishing at 3 pm

We will be there to meet you and help you to find the room.

There will be breaks for refreshments.

There are disabled toilets nearby.
The room is on the ground floor with no steps.

We will help you to join in during the meeting.

There is map with this letter. If you need help with transport, or with knowing where to go, please telephone for help.

We will pay your transport costs to come to the meeting.

Please bring any receipts with you.

If you want to talk to us about this meeting please telephone ............. (name)

......................... (telephone number)

We look forward to meeting you

.............................(signature)