the ACT NoW study

Assessing the effectiveness of Communication Therapy in the North West

information for you and your family
the ACT NoW study

you are being asked to take part in a study
what is the study about?

the study compares 2 different ways to help people with communication problems after they have had a stroke

one way is to see a speech and language therapist

the other is to see an ACT NoW visitor

we want to find out which is better
why me?

you had a stroke and have difficulty with communication

we want to include 170 people from the North West
who is doing the study?

the University of Manchester is organising the study

it is being done in your local health service

with help from
  - experts in stroke
  - experts in research
why is the study happening?

the government want us to find out the best way to help people who have had a stroke in the future

the government is paying for this study
will I see a speech and language therapist or a visitor?

who you will see will be decided by chance

half the people will see a speech and language therapist

half the people will see an ACT NoW Visitor

we do not know which will be better for you
what will they do?

a speech and language therapist will try to help your communication

or

a visitor offers one to one time and company
where will they see me?

the speech and language therapist

or

visitor

will come to see you at home or in hospital
it will take about 6 months

in the first 4 months you will see

a speech and language therapist

or

a visitor

up to 3 times a week for up to 1 hour at a time
after the first 4 months

you will have a break from support for 2 months

then an interviewer from the University will visit you and your family
what will the interviewer do when they visit?

they will make a video of you to see how your communication is at that time

they will also ask you and your family or carer about your communication
do I have to take part?

• **no** - taking part is voluntary

• you **must not** feel as though you have to take part

• you can **stop** at any time
will my information be public?

- no - all your information is **private**

- only **staff** from the study will see your **video**. They will not know who you are

- your **doctor** will be told that you are involved in the study
what are the **good** things about taking part?

- you will get **4 months** of support
  - a speech and language therapist
    - **or**
      - a visitor
  - we hope this **support** will **help** you but we cannot promise it will
- we hope this study will **improve treatment** for people who have had a **stroke** in the future
what are the bad things about taking part?

• it might be **tiring** for you

• **we do not know** if speech and language therapy or a visitor is better for you

• it may **not** be **convenient** for some people
what happens if I do not take part?

- you will get the usual **NHS** speech and language therapy for your area
what happens when the study stops?

- your part in the study stops after 6 months
- you will then be under the care of your local **NHS** service
who will be told about the results of the study?

• you and your family

• speech and language therapists

• the government and the NHS
this will be done by

• regular *newsletters*

• a *website* has been set up for the study

• *conferences*

• *scientific reports*
what happens now?

- you will be **asked** if you want to take part in the study

- if you do, you will be asked to **sign** a form. Your family can help you sign
any questions?

the **interviewer** is happy to answer any **questions** you or your family may have about the study
thank you
for reading this booklet
you can also have this information using less words and more pictures
or as a video or DVD
or an audio tape
ask the interviewer if you would like one of these