



Communication Matters: Research Matters CASE STUDY FORM



Please provide as much information as you wish. Where there are sections that you do not wish to complete in full, select 'not relevant' or 'do not wish to complete' responses.

If a suitable choice is not offered there is always a section for you to write in your own comments.

Data will be shared anonymously and anyone accessing data will have to show that they have ethically sound reasons for their enquiry. DO NOT COMPLETE any section that you would not be happy to have shared.

Date:

Please confirm that you have completed a consent form:

Yes

Consent form no.

Background Information

Age - years

+ months

Gender

Male

Female

Please tell us your COUNTRY:

a. Country of birth

b. Where you live now

c. Where you received your education

Please tell us your LANGUAGE:

a. Languages used at home

b. Languages you understand

Any other comments you want to make about your country and language ...

Personal Case Story

Whilst we will be asking very specific questions later in the form, this section is your opportunity to get across the things that matter most to you about your story.

PLEASE COMPLETE THIS SECTION WITH AS MUCH DETAIL AS YOU WISH.

You may want to come back and complete it after you have done the other sections.

How would you describe yourself?

What is most important for people to know and understand about you?

e.g. What things matter most to you?
What things are you most proud of?

Thank you for completing this section ...

Personal Case Study

In this section you will be asked questions about yourself, including things like types of communication aids used. An example of why these things are being asked may include an enquiry from a researcher who wants to understand what has been similar for individuals by clustering all the people of a certain age with a certain type of diagnosis, to see if they have had access to the same range of equipment. This may inform things like specialist assessments and follow up support.

These details are very important.

PLEASE TELL US BELOW ABOUT WAYS YOU COMMUNICATE:

1. Describe ALL the different ways you communicate.

Please select ALL relevant answers.

- ☐ body language
- ☐ body movements
- ☐ facial expressions
- ☐ gesture
- ☐ high tech aid
- ☐ light tech aid
- ☐ sign language
- ☐ sounds and vocalisations
- ☐ supported (facilitated) communication
- ☐ symbol board
- ☐ symbol book
- ☐ symbol language
- ☐ written language
- ☐ I'm not sure
- ☐ not relevant
- ☐ do not wish to complete
- ☐ Other

2. Please provide further helpful information

e.g. which symbol set do you use?

3. What is the MAIN type of communication you use:

	body language	body movement	facial expression	gestures	sign language	sounds and vocalisations
at school/college?						
at home?						
out and about?						
at work?						
other?						

	high tech aid	light tech aid	supported (facilitated) communication	symbol board	symbol book
at school/college?					
at home?					
out and about?					
at work?					
other?					

	symbol language	written language	other	I'm not sure	not relevant	do not wish to complete
at school/college?						
at home?						
out and about?						
at work?						
other?						

Other: further detail

If relevant, please list your other ways of communicating :

at school/college?

at home?

out and about?

at work?

other?

4. What is the MAIN type of communication you use to:

	body language	body movement	facial expression	gestures	sign language	sounds and vocalisations
ask questions?						
comment on something?						
make a joke?						
say no or reject something?						
give information?						

	high tech aid	light tech aid	supported (facilitated) communication	symbol board	symbol book
ask questions?					
comment on something?					
make a joke?					
say no or reject something?					
give information?					

	symbol language	written language	other	I'm not sure	not relevant	do not wish to complete
ask questions?						
comment on something?						
make a joke?						
say no or reject something?						
give information?						

Other: further detail

If relevant, please list your other ways of communicating :

ask questions?

comment on
something?

make a joke?

say no or reject
something?

give information?

5. Please tell us below how long you have been using AAC:

**a. When did you
first use AAC?**

**b. How long have
you used AAC?**

**c. Would AAC have
been useful or
necessary earlier
in life?**

.....

Any **other
comments** you want
to make about the
ways you
communicate ...

Thank you. You have completed around one quarter of the form ...



WE NOW HAVE A FEW QUESTIONS ABOUT COMMUNICATION AIDS YOU USE:



IF YOU DO NOT USE A COMMUNICATION AID, PLEASE MOVE TO THE NEXT SECTION

1. What communication aids do you use NOW and how long have you used them?

SELECT ALL RELEVANT ANSWERS

	Less than 1 year	1-3 years	3-5 years	5-10 years	10-20 years	20 years +	n/a
real objects							
photographs in a book							
photographs in an electronic book							
pictures/symbols in a book							
pictures/symbols in an electronic book							
pictures on a communication device							
symbols on a communication device							
letters/words in a book							
letters/words in an electronic book							
letters/words on a communication device							
Other							
not relevant							
I'm not sure							
do not wish to complete							

Other: further detail

Where your aid is a **communication device**, please provide further detail on devices you use

2. What communication aids have you used? Choose the approximate age when you started to use them?

SELECT ALL RELEVANT ANSWERS

	Pre-school 0-5 years	School Age 6-12 years	Adolescent 13-17 years	Adult 18-29 years	Adult 30-39 years	Adult 40-64 years	Adult 65 years +	n/a
real objects								
photographs in a book								
photographs in an electronic book								
pictures/symbols in a book								
pictures/symbols in an electronic book								
pictures on a communication device								
symbols on a communication device								
letters/words in a book								
letters/words in an electronic book								
letters/words on a communication device								
Other								
do not wish to complete								

Other: further detail

Where your aid was a communication device, please provide further detail about devices used.

3. Would a communication aid earlier in life have been useful or necessary?

.....

Any **other**
comments you want
to make about your
use of
communication
aids ...

Thank you. You have now completed over one third of the form ...



Tell Us Below How You Access Your Communication Aid:

**1. How many
squares or buttons
do you have on a
page?**

**2. What is your
access method?**

i. Indirect switch access

ii. Direct access options

**i. Indirect switch
access options:**

a. Position of
switches

head

head rest of wheelchair

wheelchair tray

armrest

knee

foot

I'm not sure

not relevant

do not wish to complete

Other

b. Scanning method:

**ii. Direct access
options:**

finger pointing

knuckle pointing

fist pointing

adapted pointer (e.g. stylus with hand grip)

eye scanning (with infrared)

eye tracking (gaze calibration)

I'm not sure

not relevant

do not wish to complete

Other

**3. Describe
previous access
methods you have
used:**

Any **other comments** you want to make about how you access your communication aid or have done so previously ...

Seating and Positioning:

1. Do you need support with seating?	Yes, I need some support	No, I don't need any support
2. How is your communication aid positioned?		
3. Do you use specialist fixing tools?	mounting system	
	specialised seating support	
	specialised limb support e.g. a splint	
	I'm not sure	
	not relevant	
	do not wish to complete	
	Other	

Any **other comments** you want to make about seating and positioning ...

1. What stops you using your communication aid as you would like?	battery life	the weather
	changing muscle tone	fatigue
	wheelchair	locations
	activities	people
	I'm not sure	not relevant
	do not wish to complete	
	Other	

2. Please explain why:

People You Talk To:

1. Who do you use your communication aid with?

	I am most likely to use my aid	I am least likely to use my aid	not relevant	I'm not sure	do not wish to complete
family					
friends					
teachers					
colleagues					
Personal Assistants					
staff/employees					
employer					
professionals I meet					
strangers					
Other					

Other: further detail

Any **other comments** you want to make about who you use your aid with ...

Specialist AAC Assessments:

1. Have you ever had a specialist AAC assessment?

Yes
No
I'm not sure

If No then please move to the next section



a. How many AAC assessments have you had?

b. Where have these assessments been carried out?

at home
supplier assessment
college
I'm not sure
do not wish to complete

specialist centre
school
work
not relevant
Other

c. Who was involved in these assessments?

Speech and language therapist
Occupational Therapist
Clinical Scientist
Teacher
Psychologist
Supplier
I'm not sure
not relevant
do not wish to complete
Other

d. What was recommended from your most recent assessment?

a symbol system
a communication book
a communication device - state below
switches
mounting system
I'm not sure
not relevant
do not wish to complete
Other

e. How was the aid funded?

education authority	health authority
social services	self
charity	I'm not sure
not relevant	do not wish to complete
Other	

f. How long did it take from the time of the assessment to getting your aid?

upto 1 month	2-3 months
upto 6 months	over 6 months
outstanding	I'm not sure
not relevant	do not wish to complete
Other	

Any **other comments** you want to make about specialist AAC assessments ...

Thank you, you have now completed about half of the form ...



Speech and Communication

The following section asks for information that may or may not be known to you. It is a helpful section as it gives understanding of why certain types of communication systems may have been recommended.

PLEASE COMPLETE THIS SECTION WITH AS MUCH DETAIL AS YOU CAN. You may have access to someone who can help you complete these questions, e.g. a Speech and Language Therapist.

This sort of information helps understanding of assessment processes being used.

Describing Your Speech or Communication:

1. Has a label been used to describe your speech or communication?	<div><div></div>none</div> <div><div></div>aphasia</div> <div><div></div>dysarthria</div> <div><div></div>dysphasia</div> <div><div></div>dyspraxia</div> <div><div></div>language delay</div> <div><div></div>social communication difficulty</div> <div><div></div>specific language impairment</div> <div><div></div>I'm not sure</div> <div><div></div>not relevant</div> <div><div></div>do not wish to complete</div> <div><div></div>Other</div>
--	---

2. Which of these best describes you?

- ☐ my speech is slurred
- ☐ my speech is quiet
- ☐ my speech is fast
- ☐ I don't use speech
- ☐ I can't use speech
- ☐ I have the words in my head but the sounds get all jumbled when I speak
- ☐ I do use my speech but I sometimes get stuck on a word
- ☐ I find it difficult to understand what people say
- ☐ I can't find the word in my head but pictures help me get my message across
- ☐ strangers find my speech difficult to understand
- ☐ family and friends sometimes find my speech difficult to understand
- ☐ family and friends always find my speech difficult to understand
- ☐ family and friends never find my speech difficult to understand
- ☐ I'm not sure
- ☐ not relevant
- ☐ do not wish to complete
- ☐ Other

3. You may find these more helpful descriptions:

a. I use my own voice so people know when I am:

- | | |
|---------------------------------------|--|
| <input type="checkbox"/> angry | <input type="checkbox"/> happy |
| <input type="checkbox"/> sad | <input type="checkbox"/> surprised |
| <input type="checkbox"/> tired | <input type="checkbox"/> uncomfortable |
| <input type="checkbox"/> upset | <input type="checkbox"/> I'm not sure |
| <input type="checkbox"/> not relevant | <input type="checkbox"/> do not wish to complete |
| <input type="checkbox"/> Other | |

b. I use my own body so people know when I am:

- | | |
|---------------------------------------|--|
| <input type="checkbox"/> angry | <input type="checkbox"/> happy |
| <input type="checkbox"/> sad | <input type="checkbox"/> surprised |
| <input type="checkbox"/> tired | <input type="checkbox"/> uncomfortable |
| <input type="checkbox"/> upset | <input type="checkbox"/> I'm not sure |
| <input type="checkbox"/> not relevant | <input type="checkbox"/> do not wish to complete |
| <input type="checkbox"/> Other | |

Any **other comments** you want to make about describing your speech or communication ...

Language and Communication Skills Assessment:

1. Have you ever had your language and communication skills assessed by a specialist?

Yes
No
I'm not sure

If No then please move to the next section



2. Who carried out the assessment?

Speech and language therapist
Teacher
Psychologist
I'm not sure
not relevant
do not wish to complete
Other

3. Please tell us how the assessment was carried out:

i. They assessed my **ability to understand sentences** using:

pictures
written words
not relevant
Other

spoken words
I'm not sure
do not wish to complete

a. The test used was:

e.g. Test of Reception of Grammar (TROG)

b. I have some test results which I can share here:

Yes
No

If yes, please give further information:

ii They assessed my **ability to understand single words (vocabulary)** using:

pictures
written words
not relevant
Other

spoken words
I'm not sure
do not wish to complete

a. The test used was:

e.g. British Picture Vocabulary Scale (BPVS)

b. I have some test results which I can share here:

Yes
No

If yes, please give further information:

3. They assessed my **ability to get my message across** using:

- | | |
|--------------------------|-------------------------|
| sign | gesture |
| sounds and vocalisations | pictures |
| symbols | written word |
| this was not assessed | I'm not sure |
| not relevant | do not wish to complete |
| Other | |

a. The test used was:

Renfrew Action Picture Test (RAPT)

b. I have some test results which I can share here:

- | | |
|-----|--|
| Yes | If yes, please give further information: |
| No | |

4. In my opinion, these assessments represented my communication skills in a way that was:

Please state why:

Any **other comments** you want to make about your language and communication skills assessment ...

Thank you for completing this section ...

Social and Emotional Responses

You may find this section difficult to answer or not relevant to you.

This can sometimes be called 'emotional lability'.

We have included this as those who helped develop this template felt these reactions meant people misunderstood how they really felt.

1. Are your emotional responses sometimes more exaggerated than other people's?

Yes

No

I'm not sure

For example your reactions seem louder, weepier, or maybe include more laughter.

2. Which of these best describes these reactions for you?

I find that I can laugh or cry very easily without knowing why and those around me are not reacting like this.

I find that I can be laughing one second and crying the next and I don't understand why, as such a heightened reaction is not how I am feeling inside.

I may shout out or use my voice in a situation where others are quiet, e.g. a meeting, I may only be agreeing or disagreeing with what is happening but my reaction seems bigger than everyone else's.

I do not experience this reaction to situations and circumstances.

I am not aware that I have this reaction to situations and circumstances but people often seem to ask me if I am ok or to be quiet.

I'm not sure

not relevant

do not wish to complete

Other

Any other comments you want to make about social and emotional responses ...

Thank you. You have completed two thirds of the form ...



Past, Present and Future

Now for some more specific things about you.

Some of the questions may feel medical. They may be things you just get on with and don't notice but they may be relevant for those concerned with service provision and product development to consider when making things work as easily as possible for others with similar characteristics to you.

Not all questions will be relevant to you.

Describing Your Schooling and Educational Experiences:

1. **Schools:**
- ☐ pre-school, special
 - ☐ pre-school, mainstream
 - ☐ school, special
 - ☐ school, mainstream
 - ☐ secondary school, special
 - ☐ secondary school, mainstream
 - ☐ co-locational school
 - ☐ I'm not sure
 - ☐ not relevant
 - ☐ do not wish to complete
 - ☐ Other

Any **other comments** you want to make about your schools ...

2. Apprenticeship:

Any **other comments** about your apprenticeship:

3. **Colleges:**
- ☐ specialist
 - ☐ I'm not sure
 - ☐ do not wish to complete
 - ☐ Other
 - ☐ mainstream
 - ☐ not relevant

Any **other comments** you want to make about your college education ...

4. University:

Any **other comments** about your university education ...

5. Qualifications achieved:

	Achieved	Working Towards
ASDAN		
NVQ		
BTec		
GCSE		
Standard Grade		
A/S Level		
A Level		
Higher Grade		
Diploma		
Degree		
Apprenticeship		
Other		
No formal qualifications		

Other: further details

Any **other comments** you want to make about your educational experiences...

Reading and Spelling Skills:

1. Describe your reading skills: I am someone who ...

2. How would you describe your spelling skills?

Any **other comments** you want to make about your reading and spelling skills...

Employment Experiences:



IF YOU ARE NOT OLD ENOUGH TO WORK, PLEASE MOVE TO THE NEXT SECTION

1. What employment experiences have you had?

- ☐ currently employed (full or part time)
- ☐ previously employed
- ☐ no employment experience
- ☐ current voluntary work
- ☐ previous voluntary work
- ☐ no voluntary work experience
- ☐ work placement experience at school/college
- ☐ I'm not sure
- ☐ not relevant
- ☐ do not wish to complete
- ☐ Other

a. How long ago was your most recent voluntary experience?

Over how long have you volunteered?

years or months?

years

months

b. How long ago was your most recent work experience?

Over how long have you been in work?

years or months?

years

months

Any **other comments** you want to make about your employment experiences ...

Where You Live:

1. How would you describe where you live?

home
home with Personal Assistant input
school
college
supported accommodation
I'm not sure
not relevant
do not wish to complete
Other

2. Are there adaptations there that aid your independence?

kitchen adaptations
bathroom adaptations
bedroom adaptations
access ramps
assistive technologies e.g. to open doors, curtains
no adaptations
I'm not sure
not relevant
do not wish to complete
Other

Any **other comments** you want to make about where you live ...

Thank you. Just one section left to complete ...

Medical

The following section includes things that do inform the types of services people get access to, as well as the range of AAC systems that may be most useful.

If you provide this type of information we would be able to see if the same decisions are being made for people with medical, rather than personal and social characteristics.

Not all questions will be relevant to you.

Medical Diagnoses:

1. Do you know if you have any specific medical diagnoses?	<input type="checkbox"/>	none	<input type="checkbox"/>	Alzheimer's Disease
	<input type="checkbox"/>	Apert Syndrome	<input type="checkbox"/>	Asperger's Syndrome
	<input type="checkbox"/>	Autistic Spectrum Disorder	<input type="checkbox"/>	Blindness
	<input type="checkbox"/>	Cerebral Palsy	<input type="checkbox"/>	Cerebral Vascular Accident
	<input type="checkbox"/>	Cri du Chat	<input type="checkbox"/>	Deaf
	<input type="checkbox"/>	Down's Syndrome	<input type="checkbox"/>	Fragile X Syndrome
	<input type="checkbox"/>	Global Developmental Delay	<input type="checkbox"/>	Hearing impairment
	<input type="checkbox"/>	Learning disability	<input type="checkbox"/>	Motor Neuron Disease
	<input type="checkbox"/>	Parkinson's Disease	<input type="checkbox"/>	Stroke
	<input type="checkbox"/>	Visual impairment	<input type="checkbox"/>	Williams' Syndrome
	<input type="checkbox"/>	I'm not sure	<input type="checkbox"/>	not relevant
	<input type="checkbox"/>	do not wish to complete	<input type="checkbox"/>	Other

2. Please provide any additional detail about your medical conditions that you feel is relevant.

e.g. if hearing impaired: your dB loss and its impact on conversation, visual impairment and everyday activities.

Recurring illnesses and conditions:

1. Are you affected by any of these recurring things?

- | | | | |
|--------------------------|-------------------------|--------------------------|------------------|
| <input type="checkbox"/> | none | <input type="checkbox"/> | chest infections |
| <input type="checkbox"/> | ear infections | <input type="checkbox"/> | eye infections |
| <input type="checkbox"/> | irritable digestion | <input type="checkbox"/> | migraine |
| <input type="checkbox"/> | spinal pain | <input type="checkbox"/> | numbness |
| <input type="checkbox"/> | I'm not sure | <input type="checkbox"/> | not relevant |
| <input type="checkbox"/> | do not wish to complete | | |
| <input type="checkbox"/> | Other | | |

2. Please provide any additional detail about recurring illnesses and conditions that you feel is relevant.

Medications:

Do you take regular medications that may impact on your communication?

Yes

No

If No, then please move to the end of the form.



1. Please tell us the effects that current medications may have on your communication:

- | | |
|--------------------------|--|
| <input type="checkbox"/> | drowsiness |
| <input type="checkbox"/> | muscle tone changes impacting on access to communication systems |
| <input type="checkbox"/> | fatigue |
| <input type="checkbox"/> | concentration and attention memory |
| <input type="checkbox"/> | mood |
| <input type="checkbox"/> | pain |
| <input type="checkbox"/> | do not wish to complete |
| <input type="checkbox"/> | Other |

2. If acceptable to you, please list these medications.

Provide any additional detail you feel is relevant.

3. If relevant, how does pain affect your movement?

using your arms
using your hands
using your head
lifting and carrying
pointing
sitting for periods of time in one position
walking with or without support
joints
muscle power/strength
involuntary muscle movements
control of voluntary movements
I'm not sure
do not wish to complete
Other

4. Please provide any additional detail about medications or pain that you feel is relevant.

You have finished this detailed form. Thank you.

Is there anything you want to add that we haven't asked about?
If so, remember that you can do this in the Case Story Section at the beginning of the form.



Thank you for taking the time to complete this form.

If you would like to follow up on anything raised in this document please contact:
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