**Working with people who have a communication impairment**

When a person has a communication impairment it is important to make sure you know how they get their message across and what you can do to help them achieve success.

It may be useful to have a discussion with the person and also a discussion with the person in the presence of their Personal Assistant.

The type of questions that would be useful to ask are outlined below:

**What methods of communication do you use?**

This may include using an electronic communication aid, signing, pointing to symbols in a communication book or using eye gaze to select letters on a computer screen. These are often collectively described as Augmentative and Alternative Communication ([AAC](https://communicationmatters.org.uk/wp-content/uploads/2019/02/What-is-AAC.pdf)).

**How easily can someone with a communication impairment get their contributions heard?**

In meetings, it is useful to know when the person with a communication impairment wants to contribute to the meeting e.g., by using a gesture like raising their hand, or speaking one word using their electronic communication aid. It may also be useful to know if the person uses some speech or vocalizes, at times.

As aided communication takes longer, one useful strategy that AAC users often use in this context is to compile their message whilst the meeting carries on. When the AAC user is ready, the meeting stops and can return to the earlier point that the individual wants to comment on. This maintains the flow of meetings. Another strategy may be for the person to use a quicker system that their Personal Assistant understands, e.g., signing or being able to understand the person’s impaired speech.

Some people also use body language or signs to indicate what they want to say. It is worth checking this out with an individual as there may be signs that are personal to them. It would be useful to tell people in the research team whether to look out for an arm or leg movement so they are ready for this.

Eye pointing (looking) can also be very powerful and easy for individuals with a communication impairment to use to indicate what they want or who they are talking about.

People with communication impairment may also have physical challenges that make the ways in which they say or indicate Yes and No rather subtle. It is vital to make sure that the Yes and No response of the individual is clearly understood by all the research team members. This could be a head nod or shake, a vocalization or a hand gesture. Ask the person to show you how they indicate Yes and how they indicate No.

For some people the use of a sign language interpreter means they can keep up with all the discussions taking place in the meeting. Additional funding may need to be found to provide this service if it was not included in the initial bid for research funding for the project.

Good practice would be to share this information with all team members.

**Support needs prior to meetings**

Things to check in terms of supporting or prompting an individual with a communication impairment might include:

* A member of the team reminding them to read and reply to emails or to read documents sent as attachments to prepare a response ready to deliver in the next meeting.
* Checking if a hard copy of the reading material needs to be sent in the post before the meeting, or whether a digital version would work.
* Checking if they use a text reader on a computer to support access to literacy. If so, are documents being made available in a format that enables them to be read out effectively? If not, the research team needs to alter the format of documents.
* Checking if the individual being included in the meeting has any visual impairment. Do they need access to Braille, large print or other supports?
* Deciding if it would be helpful to have a meeting (such as Skype) prior to any meeting with a member of the research team that will be providing support to the PI co-researcher in the meeting. The aim of this would be to clear up any misunderstandings before the meeting. This could take the form of an email conversation.
* Finding out how much preparation time they need for meetings. How long before meetings should they receive materials, to allow them enough time to read them and construct a response for the meeting? We suggest one week’s preparation time as a minimum. See this [video](https://mmutube.mmu.ac.uk/media/Public+Involvement+Powerpoint+Clip+5/0_mpio3c4a).
* Asking if they need to read through documents with a familiar support worker who can read and discuss the documents with them and ensure they understand all of them.
* The research team member supporting the PI co-researcher needs to liaise regularly to ensure support for all meetings will be covered. Holidays also need to be planned around.

**Support needed in meetings**

This could include where the assistant sits in relation to the PI co-researcher in the meetings. Their disability may lead the person to prefer for papers to be held up and the pages turned on one side of their body, to make them easier to read.

If a person uses an electronic communication aid, it can be useful for them to turn off the speech at times during a meeting to ask questions of the person supporting them, silently. The person would read the question from the screen and have a quiet conversation with the PI co-researcher and hopefully answer the query without stopping the meeting. This would mean that not everyone would have to know that the PI co-researcher had a query, which is less embarrassing for them. See this [video](https://mmutube.mmu.ac.uk/media/Public+Involvement+Powerpoint+Clip+4/0_5zpfoqmz).

Electronic communication aids can sometimes break down. It would be useful for the person supporting the PI co-researcher to know what back-up systems they have and how to use them. This may include putting the individual’s mobile phone on their knee to allow them to use text on their phone. Alternatively, a paper-based letter board could be used to spell out words, which the person supporting is then asked to read out. If this problem happens in a meeting it would be useful for the support person to be able to explain this difficulty to the rest of the meeting.

At times research teams can get carried away with discussions and they can carry on well after everyone is tired and very hungry. The person supporting the PI co-researcher needs to recognise this and suggest that the meeting breaks for all to have a drink and some food.

**Support needed for participation**

This section includes some practical and logistical factors that are worth considering in the bid development stages or delivery stages of a project.

* Does the PI co-researcher have their own Personal Assistants who are willing and able to support them during the meetings? Sometimes a PI co-researcher has specially trained medical Personal Assistants who will have to be with them at all times. In this situation, this person will be the one providing the support to the PI co-researcher and not a member of the research team.
* If not, how will the research team recruit suitable Personal Assistants for the PI co-researcher to enable them to complete their research commitments to the project?
* What training will the assistants need for general support of the PI co-researcher? If relevant, what experience do they have of supporting people with swallowing and eating challenges, and providing personal care etc. How will they be trained, and what insurance may be necessary? See this [video](https://mmutube.mmu.ac.uk/media/Public+Involvement+Powerpoint+Clip+3/0_ku55eejm).
* How long does it take to eat a meal/snack? This may affect the timetable for an all-day meeting. If not managed effectively, the person who helps the PI co-researcher with their lunch may still be eating theirs as the meeting starts again after lunchtime.
* What personal care facilities do they need to use? An accessible toilet or a changing place (with a plinth and hoist) may be required. The location of these may determine where the meeting can take place within the building.
* Medication may be needed if working a full day. This may change the requirements for a PA during meetings to someone who has the professional background to allow them to administer medication.

**Other important information**

This section covers some additional considerations, when involving PI co-researchers who have communication and physical challenges.

* How will the PI co-researchers travel to the research location? This may be in their own transport or with their own Personal Assistants. Alternatively, this may be on public transport either on their own or with Personal Assistant support.
* How long is the journey from their home to the place where the research meetings happen? Is it feasible to do this journey on a regular basis?
* Will they need parking reserving or are they Blue Badge holders?
* What is the best time to start meetings? Factor in acceptable times for leaving home to arrive relaxed. If the same Personal Assistant is driving and supporting in meetings, how long do they need so that they are relaxed and able to support the PI co-researcher effectively from the start of the meeting. Consider when staff shifts start and finish, or at what times care cover is available. This can impact on the travel time to and from meetings. It can also affect which members of support staff are able to attend which meetings. Some days may be better for meetings, for example consider the PI co-researcher’s other regular commitments.
* If the PI co-researcher’s own support staff are not able to stay for meetings, will they be escorted to the meeting room or do they need to be met at the front door?
* If the PI co-researcher’s own support staff are unable to stay, what help will be needed throughout the duration of the meeting/day?