



Communication Access and Inclusion Guideline and Procedure For the Young Stroke Service

Reference

Rose, T., Power, E., & Young Stroke Service. (2024). Communication Access and Inclusion Guideline and Procedure. Retrieved from:
<https://www.youngstrokeservice.org.au>

Important note

- This document is a draft.
- We will improve the guideline over time.
- We want to add online and video content later.

Date Effective: 11/10/2024 – Document History		
Version	Revised date	Authors
1	09/10/2024	Dr Tanya Rose, Prof Emma Power
2	22/08/2025	Dr Tanya Rose, Prof Emma Power

Acknowledgements

We **acknowledge** the contributions from the Young Stroke Service (YSS) Project Team. **Thank you.**

Definitions

We use the word **guide** in this document **to refer to guidelines and procedures.**

Who is the guide for?

This guideline was **developed** for the **Young Stroke Service (YSS).**

This guide is for **YSS:**

- consumer advisors and consumer consultants
- lived experience contributors
- clinical staff
- researchers

This is an **internal guide** specific to the YSS. It provides examples specific to the YSS. Think about your own context when using the guide.

You **need permission to modify this guide.**

Contact the YSS: YoungStrokeAdmin@florey.edu.au

How to navigate this document

Use this section to find out:

- [What content is in this guide?](#)
- [How do I use this guide?](#)
- [Why does this guide look like this?](#)
- [Who can I contact with questions or feedback about this guide?](#)

What content is in this guide?

This guide has three (3) main sections:

1. About our access guide
2. About communication access
3. How to improve communication access

This guide has six (6) appendices:

1. Interactions Checklist
2. Environment Checklist
3. Document Checklist
4. Brief communication feedback questionnaire for YSS patients and research participants
5. Patient case example
6. Lived experience contributor case example

The three **checklists** are **practical resources**. You can use the checklists to record the things you are doing to improve access.

This guide also has additional resources:



1. Links to **websites**



2. Links to **documents** and **guidelines**



3. Links to **YouTube videos** and **eLearning Modules**



4. Steps for things you can do to improve access

How do I use this guide?



Tip:

You do not have to read all the guide at the same time. The guide has sections.

You can **read bits of information at a time**.

We suggest you read all the sections over time.

Reading all the sections will help you to learn more about communication access.

- **Read** the '**Table of Contents**' to know more about the guide's content.
- This guide has **hyperlinks**. Click on the [blue and underlined text](#) to take you to another section in the guide.
- There is a [glossary](#) on **page 49**. The glossary explains the words in [green](#).

Using the checklists

Use the checklists in your everyday Young Stroke Service work.

For example, it may help to go straight to the:

- ✓ [Interactions Checklist](#) if you are:
 - planning for your first client therapy session
 - planning a meeting with contributors
- ✓ [Document Checklist](#) if you are:
 - making a brochure for your clinical service
 - writing a consent form for your research project

Why does this guide look like it does?

This guide has many pages to make it easy to read.

People with communication support needs have told us they prefer **more pages** that are **easier to read**.

This guide is **set out** in a way **to show** you **what good communication changes look like**.

Who can I contact with questions or feedback about this guide?

Young Stroke Service

Email: youngstrokeadmin@florey.edu.au

Phone: 0427 259 191

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Section 1

About our access guide

Use this section to find out:

- [What are our values?](#)
- [Why do we need an access guide?](#)
- [Who needs to use an access guide?](#)

Value statement – What are our values?

The Young Stroke Service Project **cares** about **how we interact and communicate**.

We are striving to make our **service** and **research easy to access**.

It is important for **everyone to understand** what others say and write.

It is also important that **everyone can express themselves**.

We want everyone to **feel respected** when interacting with others.

Purpose – Why do we need an access guide?

The purpose of this guide is to:

1. make us **think more about how we interact** with others,
2. give us **tools to help us communicate better** with all young people who have had a stroke,
3. help us make our **service** and **research more accessible**.

Doing these things will help us to include more young people who have had a stroke in our service and research.

The suggestions in this guide may also help people who have **cognitive difficulties**.

Scope – Who needs to use the access guide?

This guide is for **everyone who is part** of the **Young Stroke Service** project.

This includes:

- our consumer consultants,
- our lived experience contributors,
- people developing the service,
- people providing the service,
- people researching the service.

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Section 2

About communication access

Use this section to find:

- [What is communication?](#)
- [What is communications access?](#)
- [What are communication support needs?](#)
- [Who needs accessible communications?](#)
- [Principles – what do we need to know?](#)
- [Links and resources about communication access](#)
- [Communication access in our clinical service and research](#)

What is communication?

Communication involves:

- a **sender** and **receiver**,
- getting a **message out**,
- getting a **message in**,

Communication involves:

- getting **what people mean**: inference, indirect communication,
- following the **conversation rules** such as taking turns,
- **fixing mixed-up messages**: conversation repair,
- **interaction**.

Communication is **not only speech**.

People use **nonverbal communication**, such as:

- gesture,
- vocal tone,
- facial expressions.

Communication is used for:

- **giving** and **receiving information**,
- using **humour**, telling jokes,
- expressing **feelings**,
- **persuading** others,
- **learning**,
- **story telling**,
- reinforcing or creating our **identity**,
- **connecting** in meaningful ways.

What is communication access?

- **Stroke** can make it **hard to communicate** and **think**.
- You may **not know** if someone finds it hard to communicate or think.
- So, we need to communicate in ways that help people to take part.
- This help is like a **communication ramp**.
 - People who find it hard to walk need help, equipment, and ramps to move about.
 - Physical access is important. Communication access is just as important.
- So, we need to build **communication ramps** in our service and research. Some people need:
 - **many ramps** to communicate,
 - only **a few ramps** to communicate, or
 - **do not need any ramps** to communicate.
- **Everyone is different**. We aim to provide **general support** like in this guide to everyone.
- We may need to provide **specific supports to some people**.
- People in our meetings will have different needs. It can help to highlight this so everyone is aware we are helping in different ways.

- Sometimes we might not know what every individual needs. That is why we always use the general inclusion strategies.
- **Making our interactions more accessible helps everyone.** This includes people who do not have communication difficulties.
- Overall, **communication access** is about **all people** being able to **take part how they want** to.

What are communication support needs?

People may **need support to:**

- understand what people say,
- understand what people mean with their body language or tone of voice,
- express themselves in words and sentences,
- tell you their decisions,
- stay on the topic,
- be concise,
- give other people a turn,
- repair a conversation,
- speak clearly,
- read,
- write.

Who needs accessible communication?

There are many reasons why people need support to communicate.

Better communication access will help many people. For example, people who have:

- aphasia,
- dysarthria,
- dyspraxia,
- cognitive communication difficulties also called social communication difficulties,
- cognitive difficulties,
- learning disabilities,
- dyslexia,
- limited health literacy,
- vision difficulties such as hemianopia and visual neglect
- hearing loss,
- limited or no English.

People without communication difficulties also benefit when communication is made easier.



**“Accessible
communication
helps everyone!”**

Principles – What do we need to know?

- **One in three** people with stroke **have language difficulties**.
- People may have **other communication difficulties** after stroke.
- People who have communication difficulties **often get left out**.

We need to make sure people who have communication difficulties can take part in our:

1. lived experience groups,
2. clinical service, and
3. research.

People who need support to communicate have rights.

Everyone has the right to:

- **understand** communications,
- **take part in** communications,
- be communicated with in a **respectful** way.

Further resources for communication access

The links below are about Communication Access.

	Speech Pathology Australia – Communication Hub https://communicationhub.com.au/Accessibility
	SCOPE – Communication Access https://www.youtube.com/watch?v=Q0XLSANvUy0
	SCOPE – What is Communication Access – Information in Auslan https://www.youtube.com/watch?v=UYXD5QtIE7Q

The links below have **more information about communication rights**.

	United Nations Convention on the Rights of Persons with Disabilities: Article 9: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-9-accessibility.html
	United Nations Convention on the Rights of Persons with Disabilities: Article 21: Article 21 – Freedom of expression and opinion, and access to information United Nations Enable



Aphasia Bill of Rights

[Aphasia Bill of Rights – National Aphasia Association](#)



Communication Bill of Rights

[Bill-of-rights-2017_a2-1.pdf \(scopeaust.org.au\)](#)

Communication access in our clinical service and research

- We need to ask the people who use our **service** if our communication is accessible.
- We need to ask the people who do our **research** if our communication is accessible.
- It is important to **share what we are doing** to make our service and research easier to access.
- We should **record** what we do in our **medical records** and **research reports**. We can also **use the checklists** in this guide to record and check the things we do.
- We should have **Accessibility Statements**. We need these on our digital platform and website.
- Making our service and research easier to access **takes time** and **resources**.

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Section 3

How to improve communication access

Use this section to find:

- [Why do we need communication access?](#)
- **[Section 3a: Our Interactions](#)**
 - [Improving our interactions](#)
 - [Resources for facilitating positive interactions](#)
 - [Information and resources about communication access in research](#)
- **[Section 3b: Our Environments](#)**
- **[Section 3c: Our Documents](#)**
 - [Resources for making more accessible documents](#)
 - ✓ How to estimate the reading grade level
 - ✓ Understand the difference between Plain English and Easy English
 - ✓ Access the Consent Support Tool
 - ✓ How to use generative Artificial Intelligence (Chat GTP)
 - ✓ Research and medical words to explain

Why do we need communication access?

We need to make sure people with communication support needs are taking part in our service and research.

- About **one third** of **our patients** will have communication support needs.
- About **one third** of people **who do our research** will have communication support needs.

To make our service and research easier to access we **need to think about:**

1. our **interactions**,
2. the **environment**,
3. our **documents**.

(reference: Parr et al 2008)



Section 3a. Our Interactions

“We will make sure our interactions are accessible and inclusive.”

Purpose – Why do we need this information?

1. To prompt us to think more about how we:
 - **give** information,
 - **get** information,
 - **interact.**
2. To find out things we can do **to help us interact better with all young people** who have had a stroke. This includes people with **cognitive difficulties**.

Procedure – How do we do it?

1. Complete the Aphasia Institute’s eLearning Module:

Introduction to Supported Conversation for Adults with Aphasia

This module is free. It takes about 40 minutes to do.

<https://www.aphasia.ca/health-care-providers/education-training/online-options/>

The module gives the basic concepts of Supported Conversation.

You will learn:

- ✓ more about **aphasia**,
- ✓ how aphasia affects **communication**,
- ✓ ways to decrease **language barriers**,
- ✓ ways to **improve access**.

2. People who have communication difficulties may or may not have **cognitive difficulties**. We may also need to give people help with:

- remembering,
- processing,
- keeping attention,
- planning and organising,
- problem solving,
- having insight and awareness.

It may help to:

- send appointment and meeting reminders,
- give clear directions to appointment and meeting locations,
- use flow charts and diagrams to explain what you are saying,

It may help to:

- paraphrase – say the main ideas in a different way,
- signpost – use words to help people keep up with what you are saying. For example, you might use the words “first”, “next” and “finally”.
- summarise – briefly go over the main points,
- give a written summary,
- audio record appointments and meetings.

It is important to think about what each person needs.

3. Consider the following when interacting **face-to-face and online** (e.g. telehealth)

- **Acknowledge competence**
 - assume and acknowledge the person is **intelligent**,
 - reassure – say “I know that you know” at appropriate times,
 - **do not pretend you understand** when you do not.
- **Reveal competence – getting the message IN**

Things you can do to help your conversation partner to **understand**:

 - talk slowly – **do not rush**

Things you can do to help your conversation partner to

understand:

- say **one point at a time**,
- **use visuals** such as graphics or diagrams to help people understand,
- **recap** regularly – repeat your main points,
- **eliminate distractions**,
- **check if people can understand you** – look at how your conversation partner responds – take note of their facial expressions, eye gaze and body posture – this can help you to work out their level of understanding,
- ‘back up’ the conversation with a **written summary**.

- **Reveal competence – getting the message OUT**

Things you can do to help your conversation partner to **express** their thoughts:

- ask **one question at a time**,
- ask **fixed choice questions**, for example,
“Do you prefer version 1 or version 2?”
- say **“Can you show me...”** – suggest people use gesture, point to objects, or write key words

Things you can do to help your conversation partner to **express** their thoughts:

- **give time** for people to reply, especially if they are flustered,
- **use visuals** to help people express themselves – we may need to give visuals to people beforehand.

- **Verify to make the person feel understood and valued:**

- **repeat back** what you think people mean,
- **check** that **you have understood** correctly.



Source:

[Communication Tools: Communicative Access & Supported Conversation for Adults With Aphasia \(SCA™\) – Aphasia Institute](#)



Resources for further strategies:

- complete the Aphasia Institute's eLearning Module:
FREE: Introduction SCA™ eLearning module
[Communication Tools: Communicative Access & Supported Conversation for Adults With Aphasia \(SCA™\) – Aphasia Institute](#)
- Use our **Interactions Checklists** in **Appendix 1**.

Some people who have communication support needs **do not like talking on the phone**. Below are some **extra things** to think about for **phone conversations**.

- ask if you have phoned at a good time,
- be prepared to ask simple 'yes' and 'no' questions to help the person answer, if needed,
- ask if there is a better way to interact. For example, using a video call, text messaging, or meeting online.

4. Use our **Interactions Checklist** for your interactions. There are two checklists. Use the checklist that is most relevant to your YSS work:
- ✓ Checklist for interactions with our patients
 - ✓ Checklist for interactions with our lived experience contributors or research participants.

See [Appendix 1a and 1b](#).



The **Interactions Checklist** reminds us of things to think about:

- before
- at the start of,
- during, and
- at the end of our interactions.

Resources for facilitating positive interactions.

	The Tavistock Trust for Aphasia – What a difference some help makes (training video) https://www.youtube.com/watch?v=KWVoqM9jmEM
	Stroke Foundation's eLearning module Working effectively with people with lived experience to design, conduct and promote stroke research. This module is free. It takes about 40 minutes to do. https://informme.org.au/learning-modules/working-effectively-with-people-with-lived-experience-to-design-conduct-and-promote-stroke-research The module gives: ✓ tips, ✓ examples of research that worked well with people who have stroke and aphasia. See Research Development Example 3 within the module.
	Aphasia – Imagine a Life Without Words Understanding Aphasia https://www.youtube.com/watch?v=OGyOKItHS9Y
	SCOPE Quiz: How Communication Accessible are You? https://shop.scopeaust.org.au/quiz-how-communication-accessible-are-you/

Information and resources about communication access in research

In many cases, people that cannot communicate **get excluded** from research. We want all people who take part in YSS research to have a positive experience.

YSS researchers need to:

- Make people **feel valued** by:
 - ✓ giving people **time to speak**,
 - ✓ **checking** everyone is **understood**,
 - ✓ giving people a **chance to ask questions**,
 - ✓ **listening**.
- **Think about how we explain research**. Talk about the:
 - ✓ purpose,
 - ✓ process, and
 - ✓ outcome.
- Give information in **simple formats**. Use pictures or videos.
- Share the research results.
- Make sure the people we work with know:
 - ✓ **when** they need to meet with us,
 - ✓ **where** and **how** they need to meet with us,
 - ✓ **what they will do** when they meet with us.

See the research study below for more information:



Shiggins, C., Coe, D., Gilbert, L. Aphasia Research Collaboration & Mares, K. (2022): Development of an “Aphasia-Accessible Participant in Research Experience Survey” through co-production, *Aphasiology*
<https://www.tandfonline.com/doi/full/10.1080/02687038.2021.1996532>

See the research study below. The study is about how to involve people who have communication support needs in research.



Charalambous, M., Kountouri, A., Rainer Schwyter, J., Annoni, J., Kambanaros, M. (2023). The development of the People with Aphasia and Other Layperson Involvement (PAOLI) framework for guiding patient and public involvement (PPI) in aphasia research. *Research Involvement and Engagement*.
<https://doi.org/10.1186/s40900-023-00484-9>

Section 3b: Our Environments

"We will make sure our **environment** is **accessible** and **inclusive**."

Purpose – Why do we need this information?

1. To prompt us to think more about our **environments**, including:
 - physical,
 - sensory, and
 - digital.
2. To find out things we can do to make environments more accessible for all young people who have had a stroke.

Procedure – How do we do it?

- It is important that we do not only think about the physical environment.
- We also need to **think about** the **people in our environment**.
- We need to keep checking that people who have communication difficulties are taking part.
- We will include people who have mild difficulties. We will also try to include people who have more severe difficulties.
- Use our **Environment Checklist**.



See [Appendix 2](#)

The **Environment Checklist** reminds us of ways we can **change** the **culture** and **our surroundings**.

Section 3c: Our Documents

"We will think about who needs to read our documents.

We will **make** sure **our information** is **easier to read.**"

Purpose – Why do we need this information?

1. To prompt us to **think more** about the **range of documents** we use.

For example, to maximise the accessibility of our:

- emails,
- invitations and letters,
- information flyers and sheets,
- forms – consent; medical history; demographic; feedback and complaints,
- meeting agendas and minutes,
- policies,
- conference PowerPoint slides and posters,
- questionnaires,
- session summaries,
- clinical assessment reports,
- marketing and public communications,
- websites.

2. To be aware of things we can do to help make our documents better for all young people who have had a stroke.

Procedure – How do we do it?

1. Complete the **language readability activity** on **page 93**.

2. **Do more than check readability.**

We also need to make our documents:

- ✓ **relevant:** Does the document have the information readers need?
- ✓ **findable:** Can readers find the information they need?
- ✓ **understandable:** Can readers understand the information once they find it?
- ✓ **usable:** Can readers use the information to achieve the purpose?



Source:

[An international standard for plain language? Yes please! – Harmony's Research Blog \(harmonyturnball.org\)](#)

3. **Give** written **information ahead of time**.

4. **Give information** in **multi-modal formats**. For example:

- ✓ Email and follow-up phone call for people who have aphasia.
- ✓ Use **audio** or **video** format when possible. Give **choice to use captions**.

5. **Tailor** to the audience.

Documents for the **general public** should be written at or below a **reading grade of 8**.

Documents for **people who find it hard to read** should be written at or below a **reading grade of 6**.

Not all our writing will be below reading grade level 6.

But, **all our language** should:

- ✓ be **clear**,
- ✓ use **correct grammar**,
- ✓ **not use jargon**.

6. Use our **Document Checklist** to develop clear written information for everyone.



See [Appendix 3](#)

The **Document Checklist** reminds us of ways we can design and format written information.

Resources for making more accessible documents

	Stroke Association. (2012). Accessible information Guidelines: Making information accessible for people with aphasia. https://www.stroke.org.uk/sites/default/files/accessible_information_guidelines.pdf
	Templates for accessible information sheets and forms Collaboration of Aphasia Trialists https://www.aphasiatrials.org/templates-for-accessible-information-sheets-and-consent-forms/

How can I estimate the **reading grade level** of text in **MS Word**?

1. Go to File > Options.
2. Select Proofing.
3. Under 'When correcting spelling and grammar in Word', make sure Mark 'grammar errors as you type' is selected.
4. Select 'Show readability statistics'.
5. Go to Review > Check Document to see readability statistics.

Source:



<https://support.microsoft.com/en-us/office/get-your-document-s-readability-and-level-statistics-85b4969e-e80a-4777-8dd3-f7fc3c8b3fd2>

How can I estimate the **reading grade level** of my **Outlook emails**?

1. Go to File > Options.
2. Select Mail, and then, under Compose Messages, select Spelling and AutoCorrect.
3. Select Proofing.
4. Under When correcting spelling in Outlook, make sure the 'Check grammar with spelling' check box is selected.
5. Select 'Show readability statistics'.

Use Plain English or Easy English, depending on your audience:

Plain English:

- is a direct style of writing for people who can read at a reasonable level,
- helps people who want to read and understand information quickly,
- sometimes known as plain language or Everyday English,
- looks and sounds like standard forms of writing.

Easy English:

- is a writing style that helps people who find it hard to read and understand English,
- is simpler and has a lower reading level than Plain English,
- is also called easy-to-read or Easy Read,
- uses short sentences with an image or picture.

**Source:**

https://centreforinclusivedesign.org.au/wp-content/uploads/2020/04/Easy-English-vs-Plain-English_accessible.pdf

Centre for Inclusive Design | Easy English versus Plain English Guide, page 4

Access the following information guides and resources:

	This guide gives a summary of the differences between Plain and Easy English and the key features of each. https://centreforinclusivedesign.org.au/wp-content/uploads/2020/04/Easy-English-vs-Plain-English_accessible.pdf
	Plain English Guides Free guides (plainenglish.co.uk)
	Example of Easy English training and services • https://www.scopeaust.org.au/business-solutions/easy-read • https://accesseasyenglish.com.au/training/ • https://www.informationaccessgroup.com/our_services/training_workshops.html
	Tool for writing health information in plain language The SHell Editor The SHell Editor – THE SHell Editor – Health Literacy Solutions



Tool for obtaining informed consent

Consent Support Tool

[Pro-Ed Australia. Consent Support Tool \(proedaust.com.au\)](http://proedaust.com.au)

Where can I find graphics or icons to use in documents?



- <https://www.aphasia.ca/participics/>
- <https://speakeasy-aphasia.org.uk/aphasia-image-shopper/>
(donation)
- <https://mulberrysymbols.org/>
- <https://thenounproject.com/> (see free accessibility icons)
- <https://www.agewithoutlimits.org/image-library>
- <https://www.photosymbols.com/> (cost)
- <https://canva.com> (free and cost)
- YSS Icon Guide

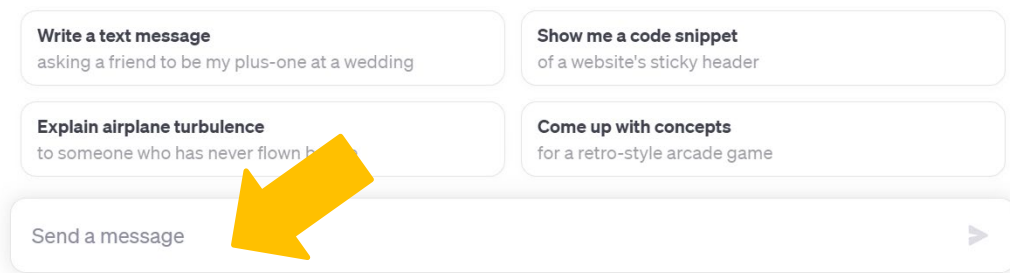


Where can I check colour contrasts?

- <https://webaim.org/resources/contrastchecker/>
- <https://davidmathlogic.com/colorblind/#%23648FFF-%23FEFE62-%23DC3220-%23FFFFFF-%23FFFFFF>

How can I use generative **Artificial Intelligence (AI)** like **CHAT-GPT** to help make language simpler?

1. Go to <https://chat.openai.com/>
2. Create an account.
3. Sign into your account.
4. Locate the “send a message” section at the bottom



5. Use the example instructions below to prompt CHAT-GPT to rewrite your information. You can ‘copy and paste’ the below instructions and your text into the “send a message” section.
6. You will then need to check what CHAT-GPT has written. Copy and paste what CHAT-GPT wrote into your own document.
7. Make changes you think it needs to be accessible, accurate, clear, and adult. Never send out CHAT-GPT information without checking it for accuracy.

An example of instructions to use in CHAT-GPT for making inclusive written information:

Rewrite the text below maintaining the key content.

Explain it in simple terms for an everyday audience or non-professional adult audience.

It should be able to be understood by an 11-year-old child.

Keep the tone suitable for an adult.

When you rewrite the information for people with aphasia:

- ✓ Use short sentences with 1 verb clause per sentence, 1 idea per sentence.
- ✓ Use active voice.
- ✓ Use simple, high frequency words.
- ✓ Explain jargon, spell out acronyms.
- ✓ Write contractions in full as two words.
- ✓ Format using bolded headings, bullet points with small chunks of text.
- ✓ Bold keywords throughout the text.

There is an example below.

This initial text is about the Australian health system. It has not been modified. The **reading Grade is 16.3**. That means the level of an academic paper for university level educated readers.

Example

The Australian health system is a complex interplay of public and private sectors, underpinned by a universal health insurance scheme known as Medicare. This system ensures that all Australian citizens and most permanent residents have access to free or subsidised healthcare. Here's an overview, focusing on the different sectors and incorporating technical language relevant to the field:

Medicare

Medicare is the cornerstone of the Australian health system, providing all Australians with access to a wide range of health services at little or no cost. Funded through general taxation and a specific Medicare levy, it covers primary healthcare services, specialist services, hospital care, and part of the cost of pharmaceuticals.

Public Sector

Primary Healthcare: Delivered by general practitioners (GPs), community health centres, and allied health professionals, primary healthcare is the first point of contact for individuals entering the healthcare system. GPs play a crucial role in health promotion, disease prevention, and chronic disease management, often acting as gatekeepers to specialist services through referrals.

Public Hospitals: Funded by state and territory governments, public hospitals provide inpatient, outpatient, and emergency services. Access to these services is usually through GP referral or emergency department presentation. Hospitals are funded through activity-based funding (ABF) mechanisms, where funding is allocated based on the number and complexity of services provided.

Specialist Services: While many specialists work in hospital settings, they also provide services in private practices. Access to subsidised specialist services under Medicare typically requires a referral from a GP, ensuring that specialist care is integrated with the patient's broader healthcare needs.

Below is the output after putting the information into CHAT-GPT. Now it is a **Flesch-Kincaid Grade Level of 4.3**. That means it is very easy to read. We have to check it is accurate. AI is often inaccurate. We cannot give it to anyone without checking. We may need to edit it or change some words if it is too simple.

Updated Example



ChatGPT

Australia's Health System Simplified

Australia has a health care system. It helps people get medical care. This system has **public** and **private** parts. **Medicare** is very important in this system.

Medicare

- **Medicare** helps everyone.
- It pays for many health services.
- Everyone pays a little for Medicare through taxes.
- It helps with doctor visits and medicines.

Public Health Care

Doctors and Health Centers:

- You see a doctor first.
- Doctors keep you healthy.
- They can send you to other doctors if needed.

Hospitals:

- There are public hospitals.
- They help with many health problems.
- You might go to a hospital if a doctor sends you.
- You might go if it is an emergency.
- The government pays hospitals for their work.

Special Doctors:

- Some doctors have special skills.
- You need a note from your regular doctor to see them.
- They focus on specific health issues.

This system makes sure you can get medical help. It helps you not worry about the cost.

How can I make a video abstract?

<https://www.aphasiatrials.org/aphasia-friendly-video-abstract-project/>



Source: Finch et al. 2023

See the research study below for more information:

Finch, E., Pierce, J.E., Pais, A., Dow-Richards, C., Reed, A., Charalambous, M., Assunção Matos, M., Wallace, S., Breitenstein, C. (2023). Preferences of people with post-stroke aphasia for aphasia research videos: An international project, *Aphasiology*, 38(4), 1-12, [doi: 10.1080/02687038.2023.2229030](https://doi.org/10.1080/02687038.2023.2229030)

Some people may find these words hard to understand:

Research words you may need to explain:

trial	randomise	efficacy
pilot	intervention	case study
tools	measures	study
outcome	feasibility	multicentre
strategies	evaluate	placebo
screen	baseline	double blind
novel	efficacy	multiple
data	quantitative	qualitative
statistics	control	domain

Medical words you may need to explain:

diagnosis	prognosis	discharge
multi-disciplinary team	pathway	procedure
acute/sub-acute	impairment	deficit
regime	primary care	admission
pre-appointment-screening	symptoms	biopsy
local application	comply	observation
screening	outcomes	predictors
care plan	adhere	



Source:

<https://www.aphasiatrials.org/templates-for-accessible-information-sheets-and-consent-forms/>

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Glossary

aphasia

- Aphasia is a difficulty with **language**. Aphasia can affect **speaking, listening, reading** and **writing**. It **does not affect intelligence**.

cognitive communication difficulties

- Cognitive communication difficulties are **changes to the thinking process that affect communication**. There may be difficulty:
 - concentrating on a conversation,
 - following **conversation rules**,
 - processing information as quickly as other people,
 - knowing when to talk and when to listen,
 - remembering things, like facts and past events,
 - using the correct words,
 - using insight and judgement, such as understanding when something is challenging,
 - planning, such as organising an event or finishing a task,
 - solving problems.

cognitive difficulties

- Difficulty with **thinking**. People may find it difficult to:
 - concentrate
 - remember information
 - solve problems
 - make decisions
 - follow instructions
 - finish tasks.

conversation rules

- Conversation rules are the **way** we **expect** people **to interact**.

There are many things that impact these rules, such as culture and how well people know each other.

Conversation rules are about:

- making eye contact,
- taking turns,
- how loudly someone talks,
- how close people stand to each other,
- how appropriate the topic is,
- how people change topic.

conversation repair

- Sometimes we do not understand other people. Sometimes other people do not understand us. Conversations repair is about the things we can try to help. For example:
 - ask people to repeat what they said,
 - tell people when we do not understand,
 - share our message again in a different way.

dysarthria

- Dysarthria is a difficulty with **speech**. Speech can sound **slurred**. There is usually muscle weakness.

dyslexia

- Dyslexia is a difficulty with **written language**. Dyslexia can affect reading comprehension, written spelling, and writing.

dyspraxia

- Dyspraxia is a difficulty with **speech**. Speech can sound **unclear**. There is difficulty planning, coordinating, and moving parts of the mouth to speak.

health literacy

- Health literacy is about how people:
 - **find** and access **health information**,
 - **read** and **understand** health information,
 - **use** health information, for example to make decisions about their health.

hemianopia

- **Loss of** vision or blindness to **part of a person's vision**. A person may not be able to see things on their left or right side.

indirect communication

- Sometimes people **do not directly say, write or draw what they mean**. So, people **need to use the context** to work out the meaning. For example, someone may ask "Oh, is that the time already?" (looking at their watch). The person means "It is time to finish now".

inference

- Sometimes people **do not directly say, write or draw what they mean**. So, people **need to use the context** to work out the meaning. For example, someone may say “Oh, it is cold.” (looking at the open window). The person’s intended meaning is asking someone to close the window.

interaction

- Interaction is about **taking part in a meaningful way**. It is about relationships and sharing experiences.

multi-modal communication

- Using **more than one way to communicate**. For example, you can speak and write.

nonverbal communication

- Sharing information **without saying words**. People may use the tone of their voice, body language, gestures, and facial expression to share their message. For example, one person in a group may say, “Let’s go to lunch.” Another person may make a ‘thumbs up’ gesture. They may also smile and nod. This nonverbal communication conveys “Yes, I agree.”

social communication difficulties

- Social communication difficulties are difficulties using **skills to interact with others**. Social skills include how we:
 - use eye contact,
 - wait for a turn to speak,
 - control the loudness of our voice,
 - understand other people's body language and gestures,
 - adjust our communication style based on who we are talking to.

visual neglect

- **Not** responding to or **giving attention** to **something a person sees**. People may not respond to things in one half of their visual field. For example, they might not read words in a sentence on the right side of the page.

Source:



We have adapted some definitions from the Communication Hub

<https://communicationhub.com.au/Glossary>

<https://communicationhub.com.au/CommunicationHub/Resources>

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Appendices

Use this section to find:

	Appendix 1: Interactions checklists Appendix 1a – Checklist for interactions with patients Appendix 1b – Checklist for interactions with our lived experience contributors and research participants
	Appendix 2: Environment checklist
	Appendix 3: Document checklist
	Appendix 4: Brief communication feedback questionnaire for YSS patients and research participants
	Appendix 5: Patient case example
	Appendix 6: Lived experience case example

Checklists

The checklists are practical resources to help you:

1. plan
2. record the things you did to help accessibility.

The Young Stroke Service may use the checklists to help show how we are making our service and research accessible.

Before:

Read the Interactions Checklist and Environment Checklist before you work with:

- patients,
- research participants,
- contributors and advisors.

Read the Document Checklist before you start any written communication.

Reading the checklists will prompt you to think about important things to do.

After:

Read the checklist when you have finished your interaction or document. Use the checklist to record the things you did.

Appendix 1a – Checklist for interactions with patients

Clinical staff in the YSS wanted a checklist for working with patients.

The Interactions Checklist has four sections:

1. Before the interaction,
2. Start of the interaction,
3. During the interaction, and
4. End of the interaction.

How do I use the checklist?

1. Read the checklist before your interaction to prompt you to think about important things to do.
2. Read the checklist after your interaction to record the things you did.

You can also use the checklist to help you self-reflect. The checklist can help you to see the things you were able to action now. Doing the checklist may also give you ideas for things to try more in the future. If you answer 'no' or 'not at all' to anything, which might happen, this may be something you can work on next time.

Interactions Checklist for Lived Experience Contributors and Research Participants

Name of person completing checklist: _____ Date completed: _____

Name of person who led the interaction: _____ Date of interaction: _____

Interaction description e.g., who was involved, where the interaction took place, interaction objective:

Before the interaction	Yes	No	N/A
I thought about if I had something complex to say.			
I made a script beforehand to help.			
Interactions with patients who need support to communicate and think takes time . It is important I do not rush. I need to be realistic about what we can do in the time we have.			
I thought about what was most important to achieve in our interaction.			
I allowed enough time .			

Interactions Checklist for Lived Experience Contributors and Research Participants

Before the interaction	Yes	No	N/A
It is important to think about all the written information I will use during our interaction. For example: consent forms, therapy instructions, assessment reports.			
I made the written information more accessible. (see Document Checklist)			
It is important to think about where our interaction will take place. I need to think about both the physical and sensory environment.			
I made the environment more accessible. (see Environment Checklist)			

Interactions Checklist for Lived Experience Contributors and Research Participants

Start of the interaction	Yes	No	N/A
I recognise and value the life experiences patients had before their stroke .			
I found out about/acknowledged the patient's life experiences, if possible.			
It is important to find out what helps people who have communication and thinking difficulties to take part .			
I asked my patient what helps them to communicate/think.			
I asked what I could do to help.			

Interactions Checklist for Lived Experience Contributors and Research Participants

During the interaction	Mostly	Sometimes	Not at all
I used supported communication strategies. (see SCA eLearning module)			
I showed respect by: • acknowledging competence • having patience • not ignoring • not defaulting to care partners unless my patient wanted this.			
I asked my patient with communication support needs to contribute. I did not only refer to family members.			
When talking, I: • said one thing at a time • slowed my rate of speech • paused after phrases and sentences • used normal intonation and volume.			

During the interaction	Mostly	Sometimes	Not at all
I provided clear instructions for what my patient needed to do. I broke tasks into small steps . I checked if each step was clear .			
I explained abstract concepts .			
I avoided indirect statements . For example, instead of saying " <i>I wonder if we should finish up there.</i> " I said, " <i>We will stop now</i> ".			
I did not use jargon and acronyms . I used lay language and explained complex terms .			
I gave information in different formats . For example: speaking, writing, drawing, video.			
I limited the amount of time people were talking at the same time .			
I looked for signs that my patient was getting tired . I added more breaks or stopped , if needed.			

Interactions Checklist for Lived Experience Contributors and Research Participants

End of the interaction	Yes	No	N/A
I kept the interaction to the time stated.			
I checked if my patient with communication support needs had anything else to contribute before ending. I allowed time for this.			
I provided a written summary of key information.			
Communication access is about tailoring our interactions to suit individual needs. The patients we are interacting with are the experts. They should decide if our interactions are accessible for them.			
I found out what my patient thought about the interaction. For example: • Did they feel supported to communicate? Did they feel respected? • Did they feel like they had a chance to contribute? • Did they understand tasks? (See items in this checklist above for questions to think about.) See Appendix 4 for a brief communication feedback questionnaire.			

Interactions Checklist for Lived Experience Contributors and Research Participants

End of the interaction	Yes	No	N/A
I have documented what I did to make the interaction more accessible. For example, in the patient’s medical record.			

My notes:

Appendix 1b – Checklist for interactions with lived experience contributors and research participants

The Interactions Checklist has four sections:

1. Before the interaction,
2. Start of the interaction,
3. During the interaction, and
4. End of the interaction.

How do I use the checklist?

1. Read the checklist before your interaction to prompt you to think about important things to do.
2. Read the checklist after your interaction to record the things you did.

You can also use the checklist to help you self-reflect. The checklist can help you to see the things you were able to action now. Doing the checklist may also give you ideas for things to try more in the future. If you answer 'no' or 'not at all' to anything, which might happen, this may be something you can work on next time.

Interactions Checklist for Lived Experience Contributors and Research Participants

Name of person completing checklist: _____ Date completed: _____

Name of person who led the interaction: _____ Date of interaction: _____

Interaction description e.g., who was involved, where the interaction took place, interaction objective:

Before the interaction	Yes	No	N/A
I thought about if I had something complex to say. I made a script beforehand to help.			
Interactions with people who need support to communicate and think take time . It is important I do not rush. I need to be realistic about what we can do in the time we have.			
I thought about what was most important to achieve in our interaction. I allowed enough time .			

Interactions Checklist for Lived Experience Contributors and Research Participants

Before the interaction	Yes	No	N/A
It is important to think about all the written information I will use during our interaction. For example: consent forms, agendas, presentation slides.			
I made the written information more accessible. (see Document Checklist)			
It is important to think about where our interaction will take place. I need to think about both the physical and sensory environment.			
I made the environment more accessible. (see Environment Checklist)			

Start of the interaction	Yes	No	N/A
I recognise and value the life experiences people had before their stroke .			
I found out about/acknowledged people's life experiences, if possible.			
It is helpful to set up interaction ' ground rules ' for group meetings. These can be informal or more formal.			
If interacting in a group, I used or co-developed interaction 'ground rules'. This may have involved talking about: • Who the facilitator was and their role. • Ways to involve everyone. Ways to 'move-on' when someone was talking a lot. • If we wanted to keep 'cameras on' for online meetings. Some people may have wanted to turn 'cameras off'.			

Start of the interaction	Yes	No	N/A
It is important to find out what helps people who have communication and thinking difficulties to take part .			
I found out ways to help people who have communication and thinking difficulties to take part. I asked people what helps them. If interacting in a group , I explained that people in the group may have different communication needs. I acknowledged that some people may not need support to take part, but others do. I also shared that sometimes we may not know what every person needs. That is why we use general inclusion strategies. I explained that I was using general strategies to help everyone to take part.			

Interactions Checklist for Lived Experience Contributors and Research Participants

During the interaction	Mostly	Sometimes	Not at all
I used supported communication strategies. (see SCA eLearning module)			
I showed respect by: • acknowledging competence • having patience • not ignoring • not defaulting to care partners unless the person wanted this.			
I asked people who have communication and thinking difficulties to contribute.			
When talking, I: • said one thing at a time • slowed my rate of speech • paused after phrases and sentences • used normal intonation and volume.			

Interactions Checklist for Lived Experience Contributors and Research Participants

During the interaction	Mostly	Sometimes	Not at all
I provided clear instructions for what people needed to do. I broke tasks into small steps . I checked if each step was clear .			
I explained abstract concepts .			
I avoided indirect statements . For example, instead of saying “ <i>I wonder if we should consider some benefits of the service.</i> ” I said, “ <i>We will all now brainstorm the benefits of the service.</i> ”			
I did not use jargon and acronyms . I used lay language and explained complex terms .			
I gave information in different formats . For example: speaking, writing, drawing, video.			
I limited the amount of time people were talking at the same time .			
I looked for signs that people were getting tired . I added more breaks or stopped , if needed.			

Interactions Checklist for Lived Experience Contributors and Research Participants

End of the interaction	Yes	No	N/A
I kept the interaction to the time stated.			
I checked if people with communication support needs had anything else to contribute before ending. I allowed time for this.			
I provided a written summary of key information.			
I gave people a way to provide feedback and to debrief , if needed.			
Communication access is about tailoring our interactions to suit individual needs . The people we are interacting with are the experts. They should decide if our interactions are accessible for them.			
I found out what people thought about the interaction. For example: • Did they feel supported to communicate? Did they feel respected? • Did they feel like they had a chance to contribute? • Did they understand the task? (See items in this checklist above for questions to think about.) See Appendix 4 for a brief communication feedback questionnaire.			

Interactions Checklist for Lived Experience Contributors and Research Participants

End of the interaction	Yes	No	N/A
I have documented what I did to make the interaction more accessible. For example, in a research participant file, research methods.			

My notes:

Appendix 2 – Environment Checklist

The Environment Checklist has three sections:

1. Before the interaction,
2. During the interaction, and
3. After the interaction.

How do I use the checklist?

1. Read the checklist before your interaction to prompt you about important things to do.
2. Read the checklist after your interaction to record the things you did.

You can also use the checklist to help you self-reflect. The checklist can help you to see the things you were able to action now. Doing the checklist may also give you ideas for things to try more in the future. If you answer 'no' or 'not at all' to anything, which might happen, this may be something you can work on next time.

Name of person completing checklist: _____ Date completed: _____

Name of person who led the interaction: _____ Date of interaction: _____

Interaction description e.g., who was involved, where the interaction took place, interaction objective:

Before the interaction	Yes	No	N/A
I planned so people with communication support needs could take part.			
I thought about the things people needed to do to take part. For example: what transport people could use; did people know who to contact if they were lost or running late; could people access the buildings; who was going to complete forms. I provided accommodations.			

Before the interaction	Yes	No	N/A
Signs and notice boards help people find where they need to go.			
I checked that our signs and notices were clear. For example: our signs included pictures or symbols, our signs were positioned at eye level/line of vision for people using a wheelchair and/or augmentative and alternative communication devices; our noticeboards were uncluttered.			
I thought about positioning to optimise face-to-face interactions. For example: seating, positioning of tables/desks.			
I had resources available to facilitate communication access. For example: pens, paper, whiteboards, augmentative and alternative communication devices, enough staff/support people.			

During the interaction	Yes	No	N/A
I included people with communication support needs. If interacting in a group, about one in three people had communication support needs.			
I checked that people with communication support needs had the things they needed and could reach important things.			
A support person was available, if needed. I explained their role. A support person may be a staff member, person with lived experience, family member or carer.			
I reduced visual distractions. For example: removed paperwork that was not needed, aligned multi-modal communication, adjusted blinds to reduce glare and shadows.			
I reduced noise. For example: closed doors.			

Environment Checklist

During the interaction	Yes	No	N/A
I made sure the space was well lit to see faces, documents, communication devices.			

After the interaction	Yes	No	N/A
Communication access is about tailoring the environment to suit individual needs . The people in the environment are the experts. They should decide if the environment is accessible for them.			
I found out what people thought about the environment. For example: • Were they able to easily get to the venue? • Could people easily follow signs to find where they needed to go? • Did people feel they had the resources/equipment they needed to take part? (See items in this checklist above for questions to think about.)			

Environment Checklist

After the interaction	Yes	No	N/A
I have documented what I did to make the environment more accessible. For example, in a medical record or research participant file.			

My notes:

Appendix 3 – Document Checklist

The Document Checklist has five (5) main sections:

1. content and language
2. typography and layout
3. emphasis and document type
4. colour and graphics
5. numbers

How do I use the checklist?

1. Read the document checklist before you start any written communication.
2. Read the checklist when you have nearly finished your document. See if there are any things you can improve.
3. Read the checklist again when you have finished your document to record the things you did.

You can also use the checklist to help you self-reflect. The checklist can help you to see the things you were able to action now. Doing the checklist may also give you ideas of things to try more in the future. If you answer 'no' to anything, which might happen, it is just something you can work on next time.

Document Checklist

Name of person completing checklist: _____ Date completed: _____

Written communication type/document description: _____

Content and language	Yes	No	N/A
Sentences are at an appropriate readability level: • general public: $\leq$ 8 grade • people with communication support needs: $\leq$ 6 grade Tips: • You can easily work out the reading grade level of your text in Microsoft Word. • It is best to work out the reading grade level for each sentence or short paragraph. • Each sentence needs a full stop. • Online readability calculators do not work for dot points or lists. Check the readability before adding these.			

Content and language	Yes	No	N/A
short words – simple words			
everyday language – no jargon – or explain jargon and terms Tips: • Assume the person is competent. Simplifying the language is helping them to show that competence. • Do not simplify your language so it looks like you are writing for a child.			
no acronyms or spell them out			
no contractions for example: use 'we are' rather than 'we're'			
consistent use of pronouns for example: use 'I/we' for the writer – use 'you' for the reader			
names of people and things rather than pronouns such as 'it'			

Content and language	Yes	No	N/A
same words and terms for the same content for example: the term 'speech pathologist' is always used rather than one time 'speech pathologist', one time 'speech therapist' and another time 'speechie'			
glossary			
short sentences			
direct writing – straight to the point – key message only			
active sentences rather than passive for example: passive sentence: You are invited to take part in a new service. active sentence: We invite you to take part in a new service.			
no judgmental language			

Document Checklist

Content and language	Yes	No	N/A
contact information for more information or help			
publication date or year			

Typography and layout	Yes	No	N/A
minimum 14-point font for body of text			
sans serif font – no cursive for example: Arial or Calibri			
minimise punctuation marks such as brackets and hyphens			
left align text centre text to help with visual neglect, but still use left alignment within the text block			

Typography and layout	Yes	No	N/A
no words split across lines			
no sentences split across pages			
dot points			
numbered lists			
no dot points or lists split across pages – repeat the heading or lead sentence if across pages			
no extra line in the space between the lead sentence and the first bullet point/number in lists			
1.5 or double line spacing for paragraphs			
logical order – important information first – consider who, what, where, when, how headings			
section text – consider colour coding, text boxes, borders			

Document Checklist

Typography and layout	Yes	No	N/A
white space around sections of text and graphics			
no important text over graphics			

Emphasis and document type	Yes	No	N/A
bold key words			
colour words in the glossary			
clear headings for sections and new topics – may be in a larger font size; no block capitals			
headings link to content			
short headings			
no underlining – only for website links			

Document Checklist

Emphasis and document type	Yes	No	N/A
no gloss paper			
documents are portable			
no fold-out sections in printed documents such as brochures folded documents can be hard for people who have a hemiparesis to hold and open			

Colour and graphics	Yes	No	N/A
colour coding for sections			
high colour contrast for text for example: black			
meaningful graphics – graphics relate to the text			
age-appropriate graphics			

Document Checklist

Colour and graphics	Yes	No	N/A
culturally appropriate graphics			
current, up-to-date graphics			
high resolution graphics			
same graphic type throughout document, if possible			
consistent placement of graphics			
graphic is placed near the related text			
consistent sized graphics			
consistent use of graphics – same graphic for same concept			
label graphics if trying to help understanding note: graphics can have other purposes, such as increasing appeal and reading ease			

Colour and graphics	Yes	No	N/A
check if people want graphics and what type, if possible note: Checking can be particularly important when writing for people with severe reading difficulties,			
'photo signature' on letters and emails – your photo, name and job title			
correct copyright/licencing/attributions/permissions to use graphics			

Numbers	Yes	No	N/A
smaller numbers as numerals			
larger numbers (e.g. 40 000) in both figures and words – check preference if possible			
fractions in words			

Numbers	Yes	No	N/A
information about numbers in multi-modal formats for example: use graphics to explain concepts about time, dates, currency, amounts, sizes			
Communication access is about tailoring documents to suit individual needs. The people reading the documents are the experts. They should decide if the document is accessible.			
I found out what the intended users thought about the document.			
I have documented what I did to make the document / my written communication more accessible. For example, in a medical record or research participant file.			

Important things to remember:

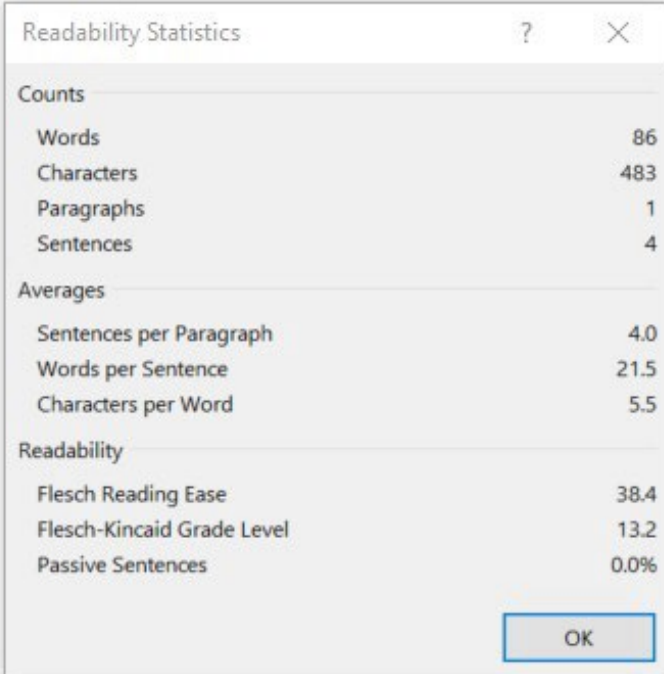
- **Accessible** and **clear documents** are **for everyone**. Not only people who have aphasia.
- **Not all design characteristics apply** to all documents and readers.
- People have different **preferences**.
- 'Accessibly designed' documents still need to be **provided in an 'accessible way'**. Use the tips in the 'Interactions Checklist' and 'Environment Checklist'.
- **People may think** some types of **graphics look 'childish'** and **'patronising'**. People who have had a stroke may not like Picture Communication Symbols. Picture boards and electronic communication devices often use this type of graphic.

My notes:

Language Readability Activity

Re-write the below text. Use shorter sentences and more simple words.

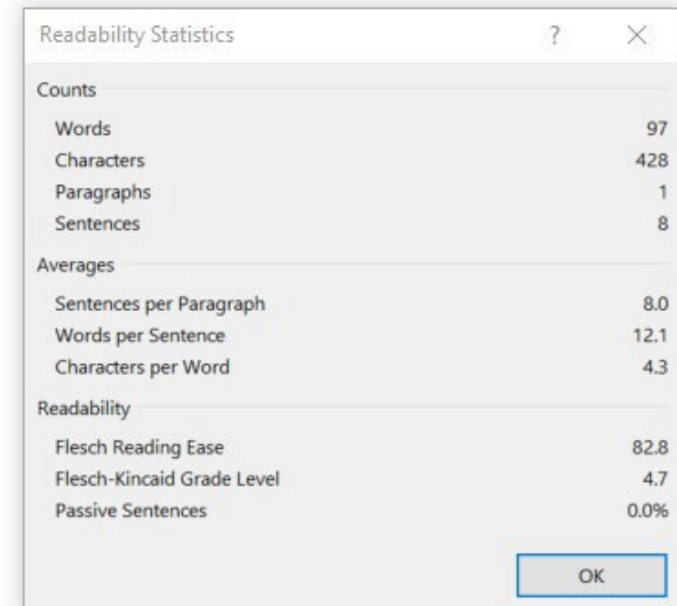
Many people experience communication and cognitive difficulties after a stroke, but these difficulties are often unknown. Just like people who have difficulty walking need assistance to enter buildings and to move around, people who have communication and cognitive difficulties also need assistance to access services and to participate. This assistance is like a 'communication ramp.' The Young Stroke Service will provide communication ramps so that all young adults who have had a stroke can access the health care services they need and choose after their stroke.



Counts	
Words	86
Characters	483
Paragraphs	1
Sentences	4
Averages	
Sentences per Paragraph	4.0
Words per Sentence	21.5
Characters per Word	5.5
Readability	
Flesch Reading Ease	38.4
Flesch-Kincaid Grade Level	13.2
Passive Sentences	0.0%
OK	

The below text has short sentences and simple words.

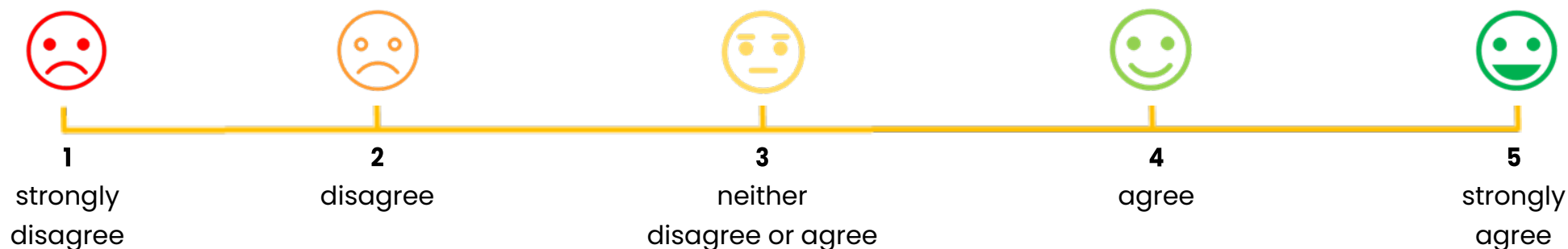
Stroke makes it hard for many people to communicate and think. You may not know when someone has these difficulties. People who find it hard to walk need help to get into buildings and to move about. People who find it hard to communicate and think also need help. They need help to access services and to take part how they want to. This help is like a 'communication ramp'. The Young Stroke Service will build communication ramps. We want all young adults who have had a stroke to get the health care they need and choose.

A screenshot of a 'Readability Statistics' dialog box. It contains three sections: 'Counts', 'Averages', and 'Readability'. The 'Counts' section shows 97 words, 428 characters, 1 paragraph, and 8 sentences. The 'Averages' section shows 8.0 sentences per paragraph, 12.1 words per sentence, and 4.3 characters per word. The 'Readability' section shows a Flesch Reading Ease score of 82.8, a Flesch-Kincaid Grade Level of 4.7, and 0.0% passive sentences. An 'OK' button is at the bottom right.

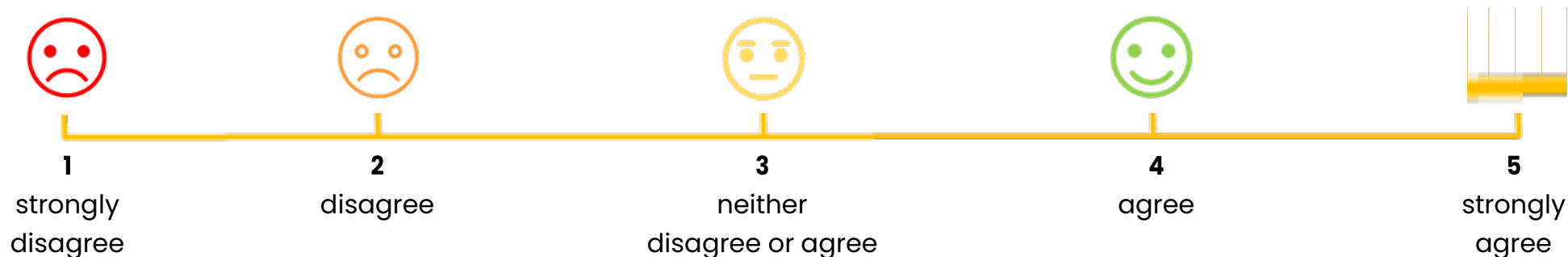
Readability Statistics	
Counts	
Words	97
Characters	428
Paragraphs	1
Sentences	8
Averages	
Sentences per Paragraph	8.0
Words per Sentence	12.1
Characters per Word	4.3
Readability	
Flesch Reading Ease	82.8
Flesch-Kincaid Grade Level	4.7
Passive Sentences	0.0%
OK	

Appendix 4 – Brief communication feedback questionnaire for YSS patients and research participants

1. Overall, I could **understand** what **other people** were **saying**.



2. Overall, I could **say what I wanted**.



3. **What** can we **do better** to **help you communicate**? _____

Appendix 5 – Patient Case Example

This example is made-up (i.e., fictional). It comes from many years of clinical experience and research on the topic.

The example is repeated three (3) times. Each version provides an example of a different level of inclusion:

1. Limited inclusive practices
2. Adequate inclusive practices
3. Maximally inclusive practices

Example background:

Sarah is 38 years of age. She had her stroke eight (8) months ago. Sarah worked as a music teacher before her stroke. She has moderate aphasia. For Sarah, this means she can understand and read information if it is in very short sentences and phrases. She can talk and write in short phrases.

Sarah's GP has referred her to the Young Stroke Service. The GP has provided Sarah's, and her partner Luke's, mobile phone numbers on the referral form. The YSS clinic staff need to arrange an intake appointment for Sarah.

1. Limited inclusive practices

Before the phone call:

The clinic staff member reads Sarah's referral form. Sarah's GP has indicated that Sarah has communication support needs. The staff member feels a bit uncertain about phoning a patient who has aphasia. The staff member decides to phone Sarah's partner Luke.

During the phone call:

The clinic staff member telephones Sarah's partner Luke. They make a time for Sarah's first online intake appointment. The clinic staff member asks for Luke's email address.

After the phone call:

The clinic staff member sends Luke an email with the appointment time and online meeting link.

2. Adequate inclusive practices

Before the phone call:

The clinic staff member reads Sarah's referral form. Sarah's GP has indicated that Sarah has communication support needs. The staff member feels a bit uncertain about phoning a patient who has aphasia. The staff member remembers the YSS Communication Access and Inclusion Guideline and Procedure. The staff member reads the 'Our Interactions' section of the guide and the 'Interactions Checklist'. Reading this information reminds the staff member of things they can do when phoning. The staff member decides to phone Sarah's partner Luke.

During the phone call:

The clinic staff member telephones Sarah's partner Luke. The staff member asks if this is the best phone number for making Sarah's appointments. Luke says that he is happy to take the call, but Sarah can also talk on the phone. The staff member then asks if Sarah is nearby and if they could be put 'on speaker' to talk to both Luke and Sarah. The staff member found it a bit hard to hear Sarah talking. There was music playing in the background.

The staff member spoke mostly to Luke, but Sarah felt happy to be there for the conversation. The staff member asked Luke and Sarah about the best ways to contact them in the future. The staff member specifically asked who they should email with the appointment details. They made a plan that emails would be sent to Sarah and a CC email to Luke.

Before finishing the call, the staff member asked what they could do to help Sarah's communication. Sarah said "write" and "slow".

After the appointment:

The clinic staff member sends an email to Sarah (cc'd to Luke) with the appointment time and online meeting link. The email contained a brief summary of the things they had spoken about.

The staff member filled-in the 'Interactions Checklist'. They also noted in Sarah's medical record the things that Sarah said helped her to communicate. The staff member also decided to complete the Aphasia Institute's eLearning Module: Introduction to Supported Conversation for Adults with Aphasia (SCA™) before Sarah's intake appointment.

3. Maximally inclusive practices

Before the phone call:

The clinic staff member reads Sarah's referral form. Sarah's GP has indicated that Sarah has communication support needs. The staff member feels a bit uncertain about phoning a patient who has aphasia. The staff member remembers the YSS Communication Access and Inclusion Guideline and Procedure. The staff member reads the 'Our Interactions' section of the guide and the 'Interactions Checklist'. Reading this information reminds the staff member of things they can do when phoning. For example, the staff member remembers about using 'yes' and 'no' questions. The staff member is busy but makes time for a brief conversation with another YSS Team who has experience talking with people who have aphasia. The staff member decides to phone Sarah. However, there is no answer. The YSS Team member had shared this may happen. Some people with aphasia find it hard to answer the phone. Sometimes people only answer the phone when they know who is calling. The staff member was prepared for this and left a brief voice mail message. They spoke calmly and did not rush. They also said that they would phone back in 10 minutes time, at 10.00am.

After leaving the voice message the staff member also sent Sarah a brief text message with the same information. The text message was simple with only key information. The message contained the YSS staff member's name, why they were phoning and when they would phone back.

During the phone call:

The clinic staff member telephones Sarah at 10.00am. Sarah answers her phone. After introducing themselves, the staff member asks a 'yes'/'no' question to check if this is the best phone number for phoning. Sarah confirms "yes". The staff member then asks a 'yes'/'no' question to check if now is an okay time for Sarah to talk. Sarah says "yes" and then "wait". There is a pause while Sarah finds Luke. The staff member can hear Luke's voice in the background. The staff member suggests they be put 'on speaker' to talk to both Sarah and Luke. The staff member found it a bit hard to hear Sarah talking. There was music playing in the background. The staff member asks a 'yes'/'no' question to confirm if there is music playing in the background. Sarah replies with "yes". The staff member politely but directly asks if they could please turn down the volume to help everyone to hear. Luke turns down the music.

Everyone can now hear much better. The staff member remembers that Sarah is a music teacher.

The staff member takes this opportunity to share they are aware of Sarah's occupation. The staff member intentionally directs their questions to Sarah. Luke responded many times, but Sarah felt happy to be included in the conversation. The staff member asked Luke and Sarah about the best ways to contact them in the future. The staff member specifically asked who they should email with the appointment details. They made a plan that emails would be sent to Sarah and a copy sent to Luke.

Before finishing the call, the staff member asked what they could do to help Sarah's communication. Sarah said "write" and "slow". The staff member also explained the next steps and that they would send an email. The email would have the staff member's name, photo and contact information. The staff member told Sarah and Luke that they could contact them if they have any questions or if they need to change their appointment time. The staff member also explained that the next appointment would be online. They checked that they were familiar with online meetings. Sarah had previously taught music online, so she was very familiar with online meetings. The staff member also shared they would email Sarah and Luke the clinic consent form before their appointment. This would give them a chance to read the form before meeting.

The staff member also used 'yes'/'no' questions to ask, "Sarah do you have any questions?", "Sarah is there anything else you would like to say?" Sarah responded with a "no" to both questions, before saying "thank you!".

After the appointment:

The clinic staff member sends an email to Sarah (cc'd to Luke) with the appointment time and online meeting link. The email contained a brief summary of the things they had spoken about. In addition, the staff member attached the consent form. The email explained they would read the form together when they meet. The consent form was written below a grade 8 reading level. The staff member also thought about the wording and format of their email. They re-read the 'Document Checklist' in the YSS Communication Access and Inclusion Guideline and Procedure. This prompted the staff member to check the reading grade level of their email. Their email was being sent to Sarah and her partner Luke. So, the staff member wrote the email below a grade 6 reading level.

The staff member filled in the 'Interactions Checklist' and 'Document Checklist'.

They also noted in Sarah's medical record the:

1. things that Sarah said helps her to communicate,
2. ways they had helped Sarah to take part. For example, using 'yes'/'no' questions worked well; turning down the music made it easier to hear.

The staff member also decided to complete the Aphasia Institute's eLearning Module: Introduction to Supported Conversation for Adults with Aphasia (SCA™) before Sarah's intake appointment.

Appendix 6 – Lived Experience Case Example

This example is made-up (i.e., fictional). It comes from many years of clinical experience and research on the topic.

The example is repeated three (3) times. Each version provides an example of a different level of inclusion:

1. Limited inclusive practices
2. Adequate inclusive practices
3. Maximally inclusive practices

Example background:

Alex is 45 years of age. He had his stroke one (1) year ago. Alex worked as a solicitor before his stroke. He has moderate aphasia. For Alex, this means he can understand and read information if it is in very short sentences and phrases. He can talk and write in short phrases.

Alex has been asked to attend a workshop with other lived experience contributors.

1. Limited inclusive practices

Before the workshop:

The Young Stroke Service sent Alex an email inviting him to take part in a workshop. The wording in the email was hard to read. Alex asked his daughter to read the email. His daughter helped a few days after Alex got the email. His daughter sent the reply. She said Alex would attend the workshop. No one from the service contacted Alex or his daughter before the workshop.

During the workshop:

Alex and his daughter made it to the workshop. They did not have clear directions about how to find the workshop or where to park. They did not have a contact name or number for who to call on the day. Alex arrived a little late. He sat with his daughter near the open door. Staff gave Alex a consent form. This was the first thing the staff did. The form asked him to sign that it was okay to audio record the workshop. Alex could not read the consent form. He got his daughter to sign the form.

Alex enjoyed the workshop. He liked meeting other people who had aphasia. At the start of the workshop, staff said they had a lot to talk about and cover. Staff spoke quickly at times. They did not write things down on a whiteboard. Alex was not always clear about the task. Alex was quiet at the workshop.

He was not always sure about when he could say something. He also did not want to hold things up.

People talked more to Alex's daughter. She made most of the contributions thinking this was her role.

After the workshop:

Alex was happy he went to the workshop. He thought everyone was very friendly. However, Alex felt he did not contribute as much as he would have liked. Also, the outcomes from the workshop were not clear to Alex. He did not know what was going to happen next. Alex also felt very tired at the end of the workshop. It was a 1-hour workshop that went on for 2-hours.

2. Adequate inclusive practices

Before the workshop:

The Young Stroke Service sent Alex an email inviting him to take part in a workshop. Staff checked the reading grade level of the email before sending it. The wording in the email was written at a grade 8 reading level. Alex asked his daughter to read the email. His daughter helped a few days after Alex got the email. His daughter sent the reply. She said Alex would attend the workshop. The staff who were organising the workshop replied. They let Alex know that his daughter was welcome to attend.

Staff made a time to talk to Alex before the workshop to find out ways he would like to take part. Alex shared it helps when people give him time to speak. He finds it hard to talk when he feels rushed. He also said that he needs people to repeat instructions. Alex's daughter said that she would drive her dad to the workshop. She also said she needed a parking space. Her dad finds it difficult to walk long distances.

During the workshop:

Alex and his daughter made it to the workshop without any difficulty. They had clear directions about how to get to the workshop and where to park. They had a reserved parking space. They were running late on the day. However, Alex's daughter knew who to contact to explain what had happened. A staff member was waiting for Alex and his daughter at the entrance to the building. Alex was able to sit away from the noisy corridor and door. The seats were set out in a semi-circle, not in rows. Alex sat near the front of the room. He could easily see the faces of all people talking. Staff closed the door and adjusted the window blinds to reduce glare.

Staff spent time explaining the workshop aims. They went through some 'ground rules' at the start.

Staff gave Alex a consent form. The form asked him to sign that it was okay to audio record the workshop. The wording in the form was written at a grade 8 reading level. It also had some graphics, large font, and white space. Alex found the form hard to read, but he gave it a try. There was time for Alex's daughter to read the form to her dad, while he looked on. Alex was then able to understand. Alex signed the form.

Alex enjoyed the workshop. He liked meeting other people who had aphasia. Staff used a calm and relaxed rate of speech. They asked Alex for his opinion. Staff gave him time to respond. He did not feel rushed to answer quickly. People directly spoke to Alex, not just to his daughter. Alex felt like he was able to contribute. Alex's daughter helped her dad, just when he got stuck. Staff had a chat to Alex's daughter before starting the workshop. She was clear about her role. Alex and his daughter felt included. Staff repeated instructions. They also wrote the instructions on the whiteboard. Staff broke the instructions down into smaller steps. Alex understood what he needed to do most of the time.

After the workshop:

Alex was happy he went to the workshop. He thought everyone was very friendly. Before the workshop ended, staff checked if Alex had anything more to add. Staff gave a summary of what they had talked about. Alex felt very tired at the end of the workshop. It was a 1-hour workshop, but the workshop kept to time. After the workshop, staff sent Alex a short email. The wording in the email was written at a grade 8 reading level. It gave a clear written summary of the workshop. The email also said what was going to happen next.

3. Maximally inclusive practices**Before the workshop:**

The Young Stroke Service sent Alex an email inviting him to take part in a workshop. Staff checked the reading grade level of the email before sending it. The wording in the email was written at a grade 6 reading level. It contained white space, bolded key words, dot points, sections, and a photo signature. Alex straight away recognised who the email was from. He understood most of the key messages in the email. Staff did not receive a reply from Alex within 48 hours, so they phoned him. Alex was very happy.

He was keen to take part in the workshop but finds typing very hard. He was feeling anxious that he had not been able to reply. He thought he might miss taking part in the workshop. The staff member spoke slowly on the phone and asked simple 'yes' and 'no' questions. They had done some training in using supported communication strategies. They made a time to meet via Zoom. They made this meeting at a time when Alex and his daughter could join.

Alex, his daughter, and the staff member met on Zoom. The staff member explained what the workshop was going to be about. The staff member told Alex's daughter she was very welcome to attend, and other family members would be there. They all spoke about ways Alex would like to take part and what helps him to communicate. Alex had taken part in other workshops. He shared what he liked and did not like about previous workshops. Alex shared it helps when people give him time to speak. He finds it hard to talk when he feels rushed. He also said that he needs people to repeat instructions. Alex's daughter said that she would drive her dad to the workshop. She also said she needed a parking space. Her dad finds it difficult to walk long distances.

During the workshop:

Alex and his daughter made it to the workshop without any difficulty. They had clear directions about how to get to the workshop and where to park. They had a reserved parking space. They were running late on the day. However, Alex's daughter knew who to contact to explain what had happened. A staff member was waiting for Alex and his daughter at the entrance to the building. Alex was able to sit away from the noisy corridor and door. The seats were set out in a semi-circle, not in rows. Alex sat near the front of the room. He could easily see the faces of all people talking. Staff closed the door and adjusted the window blinds to reduce glare.

Staff spent time explaining the workshop aims. The group co-produced 'ground rules' at the start of the workshop. Some people did not know about aphasia. Staff let everyone know what aphasia is. Alex told everyone he needs more time to get his thoughts out. Staff gave Alex a consent form. The form asked him to sign that it was okay to audio record the workshop. The wording in the form was written at a grade 6 reading level. It also had some graphics, large font, and white space. Staff used the 'Document Checklist' when they made the form. Alex found some parts of the form a bit hard to read, but he gave it a try.

A staff member read the form to everyone. Staff checked with each person at the workshop if they had any questions. Staff had also sent everyone a copy of the consent form. So, everyone had a chance to read the form before the workshop. Alex had looked at the form with his daughter before the workshop. He did not feel pressured or embarrassed about needing help to read the form. Alex understood the form. Alex signed the form.

Alex enjoyed the workshop. He liked meeting other people who had aphasia. Staff and all helpers used a calm and relaxed rate of speech. They asked Alex for his opinion many times. Staff gave him time to respond. He did not feel rushed to answer quickly. At times staff referred to the 'ground rules' that the group had set up at the start of the workshop. This helped to politely stop others from talking too much. It helped everyone to get a turn. People directly spoke to Alex, not just to his daughter. Alex's daughter helped her dad, just when got stuck. Staff had a chat to Alex's daughter before starting the workshop. She was clear about her role. Alex and his daughter felt included. Staff also referred to Alex's career. Staff asked Alex to think about his work experiences when contributing. Staff repeated instructions. They also wrote the instructions on the whiteboard. Staff broke the instructions down into smaller steps.

Staff also sent out the workshop agenda before the day. The agenda helped everyone know what they needed to do at the workshop. Staff checked-in with everyone to make sure tasks were clear. Alex understood what he needed to do. This made him feel confident.

Everyone at the workshop had a helper assigned to them if they wanted one. There were pens and paper on all tables. The helper wrote down key words during the workshop. Staff also saw people were feeling tired during the workshop. There was a short break half-way through the workshop.

After the workshop:

Alex was happy he went to the workshop. He thought everyone was very friendly. Before the workshop ended, staff checked if Alex had anything more to add. Staff gave a summary of what they had talked about. Staff wrote key words on the whiteboard when they spoke. Alex felt very tired at the end of the workshop. It was a 1-hour workshop, but the workshop kept to time. The short break really helped. Staff had also checked when scheduling the workshop what time of day was best for most people. The workshop was in the morning. Morning time suited most people best because they were less tired then.

After the workshop, staff sent Alex a short email. The wording in the email was written at a grade 6 reading level. The email used many of the tips in the 'Document Checklist'. It gave a clear written summary of the workshop. The email also said what was going to happen next. Staff also made a brief video summary.

Everyone who went to the workshop could get the video summary. Some people who did not have aphasia said they preferred to listen to information. Staff also spoke with Alex and his daughter to get their feedback about the workshop. Staff asked if they could change anything for next time to improve their experience.