Level 1 / 114 William Street T 61 3 9642 4899 office@speechpathologyaustralia.org.au
Melbourne Victoria 3000 F 61 3 9642 4922 www.speechpathologyaustralia.org.au

Speech Pathology Australia

FAQ for SPA members
Informed Consent

Please find below responses to questions Speech Pathology Australia (SPA) members frequently ask about consent.

If you require further clarification, please contact SPA by phoning 1300 368 835, or emailing ethics@speechpathologyaustralia.org.au

What is informed consent?

Informed consent is a person's decision, given voluntarily, to agree to a healthcare treatment, procedure or other intervention that is made:

- Following the provision of accurate and relevant information about the healthcare intervention and alternative options available; and
- With adequate knowledge and understanding of the benefits and material risks of the proposed intervention relevant to the person who would be having the treatment, procedure, or other intervention.

(Australian Commission on Safety and Quality in Healthcare)

There are four components of informed consent in healthcare:

- The individual must have the capacity to make the decision;
- You must disclose information about the test, intervention, or treatment, any risks, and benefits and how probable these risks and benefits are to occur;
- Informed consent relies on giving all relevant information in a clear and easy to understand manner to anyone who you provide services to. The information must be complete, to support the individual who is giving consent to understand what they are agreeing to and how this may impact them.
- Finally, this consent needs to be given without coercion or duress, can be removed at any time and needs to be re-established when any changes are made.

What are my ethical obligations under the SPA Code of Ethics?

As Speech Pathologists we adhere to the standard:

2.1 Consent, privacy and confidentiality

We ensure informed consent has been obtained from clients for the services we offer, including for the information we collect and share and the cost of the services.

We treat as confidential all information we receive and handle in the course of our professional services.

We comply with relevant laws.

We maintain secure storage of digital and other files and best practices regarding privacy and security of personal information.

We do not disclose information about our clients, or confidences they share with us, unless:

Our clients consent to this; or

The law permits or requires us to disclose it.

Gaining informed consent is consistent with support for a client's autonomy, and is aligned with the Communication Bill of Rights.

What are some situations where an individual may need additional support to provide informed consent?

This may occur when someone does not have sufficient understanding of the language in which consent forms are written or the words or terminology you are using to explain the treatment or intervention. This may include individuals where English is not their first language, or clients with a communication difficulty or complex communication needs, such as AAC (Augmentative & Alternative Communication) users, individuals who have a brain injury, intellectual disability or deteriorating cognitive abilities.

Additionally, informed consent might not be supported if your explanation contains jargon or speech pathology terms that this person may not understand. Lack of informed consent also occur in individuals with low health literacy, those who are anxious, dysregulated, distracted, or who are unfamiliar with medical or scientific terminology.

If English is not the first language of the individual giving consent, it is strongly recommended to use a professional interpreter and/or translator as required rather than a family member or friend who may not be familiar with medical words or other technical language and to make sure the message is accurately conveyed. It may be appropriate to modify how information is provided, such as use of Easy English, to support understanding of the information necessary for the person to give informed consent.

For individuals who use sign to communicate, it is strongly recommended that a professional interpreter, rather than a family member is used, as they will be more familiar with medical words or other technical language.

For individuals using icon-based communication or pre-generated text, it is possible that new icons or messages will need to be added into the system and the individual may need to be taught what these icons mean, and in what situations they might need to use them.

For individuals who have intellectual disability or cognitive deficits/dementia please consult the decision-making tree below. You may need to collaborate with other professionals, such as a psychologist or medical practitioner, to ensure you have adequate information regarding supports this person needs to provide informed consent.

Other situations can be where an element of the treatment has changed, for example changing from a focus on articulation to an eating intervention, without prior discussion and consent from the client.

What should I do if the individual receiving the intervention is not able to give informed consent?

Consult the decision-making tree below, to see if there are any supports that would assist the person to understand and express their wishes, such as modifications to how the information is being delivered or other supports for communication. Consider strategies such as asking comprehension questions or asking the individual to explain what the information provided means to them. Ensure that the client has access to any supports they typically use such as AAC, glasses and/or hearing aids and consider an optimal time to have the discussion when they are alert and able to process new information.

If this person is a minor, a caregiver may be able to consent. If this person is an adult, they may have appointed another person to make decisions on their behalf ('substitute decision maker'). It is important to check who their substitute decision maker is and involve them in the discussion if the person already has this arrangement in place.

What can I do if there is a change in someone's ability to give informed consent?

There is an onus on members to notice when there is a change in the therapeutic relationship and act accordingly. This includes, but is not limited to;

Ruling out that there is no medical basis for this change that needs further investigation by their doctor;

Ensuring that the emotional and sensory regulation needs of this person are being met;

Consulting with other involved professionals if there is a discrepancy between the presentation of the person in front of you and information provided as background.

How do court orders influence informed consent?

When gaining consent, ask if any court orders are in place. These could include, but are not limited to; parenting orders, instructional directives, and guardianship orders. These documents need to be viewed and the requirements followed while consent is being gained, and also if ongoing intervention is going to be provided.

Can a mature minor consent or remove their consent? Can this overrule caregiver wishes, even if the caregiver is paying for the session?

This is a complex consent decision making scenario, please contact the SPA ethics team to discuss the individual nuances of your situation. You may require individualised legal advice to understand how to proceed.

If a mature minor meets the criteria to consent, they may be able to refuse an assessment or intervention, it would be prudent to seek legal advice in this situation. When gaining consent initially regarding intervention provided to a mature minor this should be addressed with both the client and caregiver. For example, a 16-year-old with typical intelligence may be able to consent to their own assessments or intervention, and speech pathologists need to understand the legal context in this situation.

Who gives consent when a child is in foster care?

This depends on the state you are in, and the type of consent required.

How does informed consent relate to confidentiality?

In order to communicate with other professionals about your client or patient, informed consent is necessary. You will also need informed consent to communicate with the important people in the client's life, for example the family friend who sometimes brings the child to your session, the schoolteacher when you take the child back to class, or the child of a client you see in an aged care home. Consent

to communicate with specific people should be documented in the clients file and reviewed at regular intervals.

Do I need written consent or is verbal consent sufficient?

This depends on the assessment or procedure, for relatively low risk treatments or assessments verbal consent might be sufficient, with a written record of the conversation. However, for more invasive, intrusive, or complex treatments and assessments written consent is required.

Written consent is required for commencing intervention, assessment and sharing information, and if any major changes occur- for example if a condition were to deteriorate, or new information came to light changing the best evidence-based approach to intervention.

The type of documentation you should keep demonstrating informed consent has been obtained will depend on the context of the service provision. For example, when working with a client or patient who is refusing texture modifications to diet or fluids, see Informed Choice and Shared Decision Making with People who Eat and Drink with Acknowledged Risk Practice Guideline.guideline.

How often do I need to gain consent?

Consent for any assessment, treatment and privacy/sharing information should be gained:

- Prior to assessment;
- At the start of all procedures;
- When there is a major change in any of these procedures for example changes to the intervention focus, client presentation or long-term goals;
- concern or doubt about a course of action;
- If the client expresses a wish to change or remove their consent;
- If new information comes to light or if a new request is made which requires consent from the client; or
- For long standing clients, consent for treatment plans should be reviewed and discussed on a yearly basis, when goals or plans are due for review, or whenever there is a change in treatment or circumstances.

What happens if I am not able to obtain informed consent?

This may be dependent on organisational context or policies. In general, you are not able to provide an intervention or service without informed consent, however, you should always understand the specific requirements of your workplace or organisations where you are acting according to a service agreement.

How does this affect me as a business owner?

As a business owner you will need to have a privacy policy, even if you are a sole practitioner. You need this policy to cover how informed consent is obtained from a person you are working with, how you will act to gain and record informed consent in a variety of contexts with clients demonstrating a range of functional capacity and when you need to review or revise this consent.

Additionally, if your business uses images of clients in advertising you will need to seek informed written consent for using photos of clients on your website and/or social media platforms. This might include if the image is sharable or how long the image will remain on social media. For more information on this, please see the SPA Advertising Policy and Informed Consent for Use of Client Images Online FAQ.

Do I need to gain informed consent if I see a child at school or an educational setting?

When contacted by a parent/guardian to provide services for a child you need to gain informed consent for the services provided, wherever that location is. If your service agreement is with the parent, consent must be given by the parents/guardian for the speech pathologist to discuss any aspect of the child's therapy program or support needs with staff at the school. You should discuss with the parent/guardian what sort of information you will be providing to and obtaining from staff at the school and which staff this will involve. You should obtain the parent's permission in writing prior to this occurring and if the situation is likely to change (e.g., there is a change of staff) then reconfirm the parent's consent to disclose/collect information.

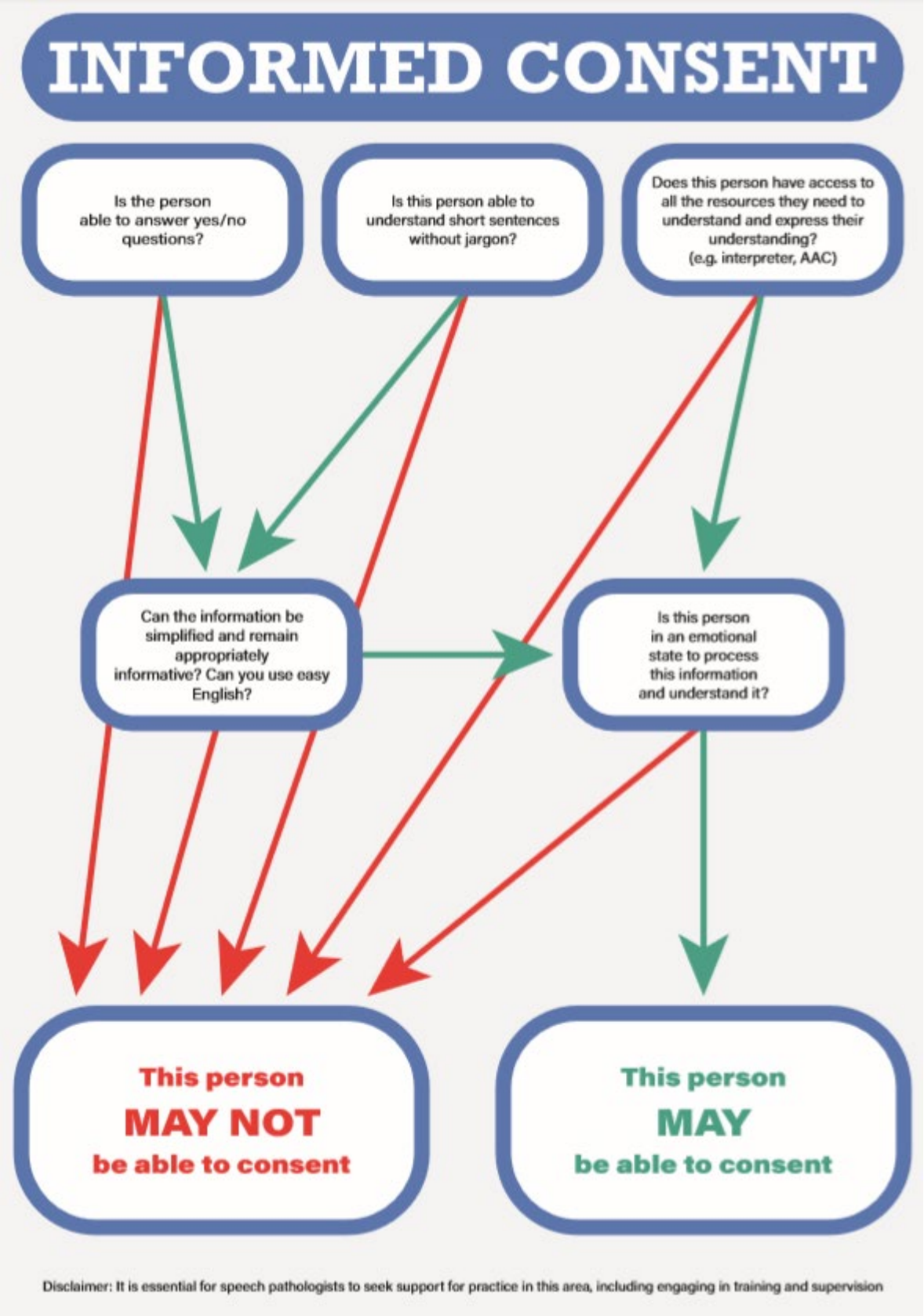
If you are employed directly by the school or educational organisation, consent for assessment and intervention must still be gained prior to commencing service provision from the parent/caregiver. Who gains consent, what services are consented to, and how written consent is stored/accessed may need to be discussed with the school.

When working in a school, either as a contractor or employee, it is important to consider what services you are providing and whether consent from the parent/guardian is required

For example:

- you are working in a school as a contractor. The school asks you to observe a student in a class and talk to the teacher about the child's communication difficulties and strategies to support that child, this action would require informed consent from the parent /guardian, as you are providing specific professional advice regarding an individual.
- you are employed by the school to provide focused support for specific students who need additional supports to access the curriculum, but not individual therapy. You are still providing individualised professional services and informed consent is required.
- you are asked to observe a whole class and provide general ideas about language enrichment or similar, i.e., support for the teacher to work with the whole class. In this situation you possibly would not need consent if you do not provide specific advice about an individual, however, you would need to be very careful that you do not identify a particular child's needs in that situation. You may need to seek specific advice regarding the situation.
- SPA recommends that a speech pathologist providing this type of service should work with the school to advise parents it is happening and give them a chance to ask questions or an 'opt out' option, so that they are fully informed about what is provided for their child.

Can this person give informed consent?



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Original June 2022

Updated October 2023, August 2024