Consent

Introduction

Information on consent, including:

- how consent is gained, managed and documented
- what to do when an individual is unable to give consent
- legislation and guidance relating to consent
- resources to support discussions around consent

What is consent?

Consent is the process by which an individual gives permission for something to happen.

The principles of consent form an important part of clinical ethics and human rights. They are defined and protected in international and national legislation.

For consent to be valid, it must be fully informed and given freely by someone with capacity.

- Consent may be verbal or non-verbal, written, or, implied by the actions of the service user, for example, attending the appointment implies or assumes consent to the appointment.
- The acquisition of consent must be transparent (who, when, why, what) and clearly documented.
- Consent and capacity to consent are dynamic and ongoing processes, dependent on each decision, in each context, in each moment of time.
- Consent is continuous and individuals hold the right to withdraw consent at any time.
- Failure to gain proper consent may result in claims of clinical negligence.

Scope of this guidance

Consent is a core principle within speech and language therapy, and applies across multiple areas of practice. This guidance outlines the role of consent in the following contexts:

- consent for speech and language therapy
- consent to record
- consent to share confidential information
- consent in research

Responsibilities

To ensure that they are gaining valid consent, speech and language therapists should:

Promote:

- individuals’ rights and choices, including the right not to consent to decisions and or actions affecting them
- support and empower individuals to participate in decision-making.

Provide:

- adequate, accessible information to enable individuals to provide informed consent as appropriate
- all relevant information to support individuals in making their own decisions, including those relating to issues of risk and consent.

Work with:

- relevant legislation and other frameworks, including where individuals are not able to give consent
- colleagues within and across settings, sectors and professions in the best interests of service users
- local policy or protocol where mental incapacity does not allow the gaining of consent to share service users’ information.

Ensure:

- the process by which consent is gained and given is valid
- consent and the process of consent is clearly documented
- that if consent cannot be lawfully gained, they seek an alternative lawful basis for interventions.

National legislation and guidance

It is important to understand consent within the diverse range of UK and International laws, as these affect the principles of how consent is defined, obtained and managed in differing contexts.

It is also important to be clear that the legislation governing consent to lawfully process personal data differs from patient consent to treatment. Please refer to our **information governance guidance** for details about managing personal data.

HCPC have released some guidance on **consent principles** aimed at improving informed decision-making and reducing patient and service user harm.

The relevant National Legislation related to consent is referenced throughout sections of this guidance, but key pieces of legislation include:

- **Adults with Incapacity (Scotland) Act (2000)**
- **Mental Capacity Act (2005), in England and Wales**
- **Mental Capacity Act (Northern Ireland) 2016**
- **Human Rights Act, 1998 (Adults)**
- **Children Act, 1989 (Children)**

Consent for speech and language therapy

Individuals have a fundamental legal and ethical right to determine what happens to their own bodies. Valid consent to treatment is therefore absolutely central in all forms of healthcare, from providing personal care to undertaking major surgery. Seeking consent is also a matter of common courtesy between health professionals and individuals.

All service providers must have clear guidelines in place, relating to the gaining and recording of consent. These must be in line with local and national policy.

Consent must be fully informed, given freely and be specific. It should include information on how/when/why/what.

HCPC Standards of Conduct, Performance and Ethics (2024) describe informed consent as:

Permission for a registrant to provide care, treatment or other services, given by a service user, or someone acting on their behalf, after receiving all the information they reasonably need to make that decision.

Standard 1.4 states:

You must make sure that you have valid consent, which is voluntary and informed, from service users who have capacity to make the decision or other appropriate authority before you provide care, treatment or other services.

The RCSLT recommends that SLTs observe:

- inclusion and shared decision-making
- legal entitlement to consent
- capacity to consent
- gaining consent
- documenting consent

Gaining consent

Planned services and care must be explained in an accessible format. This is essential if someone is to understand what they are consenting to.

- Consent may be given orally, in writing, or non-verbally (implied) by the service user’s actions. The format in which consent has been gained should be recorded.
- Written consent is advised for higher-risk treatments, such as FEES or videofluoroscopy.

- Each professional involved in an individual's care must gain informed consent.
- Care must be taken to respect the individual's wishes.
- A person capable of giving their consent has the right to refuse care. They must be made fully aware of the risks of refusing that care.
- Additional consent must be gained from the service user for students, or other third parties, to be present.
- Additional consent must be obtained if content is to be used in research. (see section 'consent and research' later in this guidance.

As consent is an ongoing process, rather than a one-off decision, therapists are also required to ensure that an individual/carer continues to give consent throughout the process of service involvement. Services will need to consider, in relation to each client group, at what points in an individual's journey through the service, it may be appropriate to seek further consent and how this might be documented.

Consent when working with adults

Any individual over 16 has the right to give informed consent for health and social care. See also the 'Capacity to Consent' section later in this guidance.

Consent when working with children and young people

Consent for assessment and intervention of children under the age of 16 will normally be sought from the parent/guardian. Young people aged 16-17 are presumed in law to be competent. However, parental decisions may override the young person's decisions if it is in the young person's best interests.

However, children under the age of 16 can give consent providing that:

- the practitioner raises the issue of their involvement with the parent/guardian and documents their response, and
- the child has sufficient maturity to understand the nature, purpose and likely outcome of the assessment or intervention

Children younger than 16 require a person with 'parental responsibility' to give consent on their behalf for services delivered over the internet (for other services follow the**Gillick Competencies**).

Efforts should be made to encourage the child that his/her parent/guardian should be informed (except in circumstances where it is clearly not in the child's interest to do so) – (NHS Scotland, 2004).

Those with ‘parental responsibility’ as defined in the **Children’s Act (1989)** may consent to care for an individual who is under 16. Generally speaking, consent given by one person with parental responsibility is valid, even if another person with parental responsibility withholds consent.

This may be:

- one of the child’s parents
- legally-appointed guardian
- a person in whose favour the court has made a residence order concerning the child
- a local authority designated in a care order in respect of the child
- a local authority or other authorised person who holds an emergency protection order in respect of the child.

However, the **United Nations Convention on the Rights of the Child** asserts the right of children to give and receive information, to give an opinion and have their views considered. The term **‘Gillick Competence’** refers to the capacity of those under 16 to make some informed decisions, based on their understanding and maturity.

When services are provided in an educational setting, the headteacher cannot give consent for a child to be seen. This must come from a person with parental responsibility.

Foster parents do not automatically have full parental responsibility and clarity on this issue should be sought from those concerned (Children Act, 1989).

Where therapists are practicing in environments where consent cannot be assumed, carer consent must be obtained to see the child, e.g. screening in nurseries/schools.

In cases where the right to consent cannot be determined, the decision may be made in Court.

Capacity to consent

Assessment of capacity is ongoing, for each decision in each moment in time.

For detailed information on capacity, see **mental capacity and supported decision making**.

Anyone who lacks capacity to give informed consent should be treated in his or her best interests.

“Best interests” should include consideration of:

- past and present wishes
- beliefs and values
- advance directives
- personal Welfare Attorney
- Independent Mental Capacity Advocate (IMCA)
- lasting power of attorney’s authority to consent
- deputy appointed by the Court of Protection
- the opinions of people who know the person well.

Best interest decisions must be reviewed regularly, as they are subject to change. If the decision concerns the provision or withdrawal of life-sustaining treatment, the person making the best interests decision must not be motivated by a desire to bring about the person’s death.

Details of the assessment of capacity and the conclusion reached should be recorded in the notes in the same format as the documentation for consent.

Documenting consent

Consent should be routinely recorded in case notes.

Individuals should be fully informed about any proposed interventions and consent should be gained for all care. It is good practice to provide a written information leaflet explaining any procedures/interventions.

Speech and language therapists should document consent in the individuals' record including details of:

- what information was given
- what time consent was gained
- third parties which the consented information may be shared with
- how consent was gained and given, ie written, verbal, non-verbal
- If care is required to be given in best interest.

It is recommended that written consent is obtained for:

- individual participation in teaching exercises
- intervention involving working with a student
- individual participation in research projects
- photographic or audiovisual recordings
- use of invasive procedures
- use on social media/online.

SLTs must ensure that where an individual does not accept any aspect of assessment or intervention, the therapist should respect that decision and withdraw, recording the situation in the case notes.

Withdrawing consent

Individuals should be made aware at the time of gaining consent that they are entitled to withdraw that consent at any time.

There should be clear processes in place for the withdrawal/review of the parameters of consent.

Invalid consent

You will not have valid consent if:

- you have any doubts over whether someone has consented
- the individual doesn't realise they have consented
- you don't have clear records to demonstrate they consented
- there was no genuine free choice over whether to opt in
- the individual would be penalised for refusing consent
- there is a clear imbalance of power between you and the individual
- the consent was bundled up with other terms and conditions
- the consent request was vague or unclear
- you use pre-ticked opt-in boxes or other methods of default consent
- your organisation was not specifically named
- you did not tell people about their right to withdraw consent
- your purposes or activities have evolved.

Consent to record

Consent for audio and visual recordings is required. Purpose and possible future use must be explained, including use for:

- service users’ care
- teaching
- assessment
- audit
- research
- public media, such as the internet, social media, television and radio.

For those who lack capacity to consent, it should be sought from their legal guardian.

Types of recordings

Primary/personal: photos taken purely for personal use by consenting individuals are exempt from data protection laws, for example, a parent taking a photo of sports day for their personal album or a service user recording their consultation.

Secondary: e.g. teaching, use on school display board. They could be used to provide detailed information of scope-of-use; timescales of anticipated use. Consent should be sought with the understanding it can be withdrawn at any time. X-rays or endoscopic images may be used for secondary purposes without consent, so long as all patient identifiable information is removed. However, wherever possible, it is good practice to seek consent.

Tertiary: use of recordings, ie for publication in newspapers, on the internet, social media or TV or other types of video or broadcast must:

- have written consent of the service user or legal guardian
- have the agreement of the organisation where recording is being made
- include making the service user and/or legal guardian aware that it may be impossible to withdraw consent at a later date.

Consent to share confidential information

In the UK, the disclosure of confidential information in a healthcare context must adhere to relevant legislation, including the common law duty of confidentiality, the Data Protection Act 2018, and the UK GDPR. In some instances, consent is required to share confidential information. Please refer to our **confidentiality guidance** for further information.

Consent and research

Consideration of consent for participation and use of data is a fundamental part of the research process, but this may differ from the consent processes around treatment. SLTs should refer to specific regulations and guidance for research:

- **UKRI Economic and Social Research Council**
- **Health Research Authority**
- **Information Commissioner's Officer**

NHS England has developed a **National Data Opt-out Programme**, supporting patients to make an informed choice about whether their data is used only for their care and treatment or also for research and planning. The service is mandatory for health and adult social care organisations in England.

Resources

The resources listed below include some useful tools to support discussions around consent, as well as useful toolkits and sources of further information.

Please note: the resources on this page are provided for informational purposes only. No endorsement is expressed or implied, unless otherwise stated. While we make every effort to ensure this page is up to date and relevant, we cannot take responsibility for pages maintained by external providers.

- Aphasia friendly ebooks for discussing choices when leaving hospital, alternative routes of nutrition, quality of life feeding.**Available from Apple Books**.
- Aphasia Institute**Communication Aid to capacity assessment (CACE) (PDF)** a tool for supporting communication access on the decision of where to live.
- Black Sheep Press**Supporting adults with communication impairments to make decisions**, pack of resources designed to assist professionals from a number of disciplines and settings, to help adults with communication impairment participate in decisions relating to their care, home circumstances and hospital treatment, supporting good practice under the Mental Capacity Act (2005).
- **British Medical Association: Children and Young Persons Toolkit**is a copyright-free resource presented in easy-to-read information cards. They cover: assessing competence; parental responsibility; consent and refusal; best interests; children and young people's health information; 16 and 17-year-olds who lack mental capacity.
- **Mental Capacity Act Code of practice** (2013)
- **National Institute for Health Research: Research Delivery Network** has produced a set of resources called, "**Engaging with people who have aphasia: A set of resources for stroke**". Aimed at helping people with aphasia to participate in research studies, they include a flowchart for gaining informed consent and aphasia-friendly images for describing research projects.
- NHS England –**Accessible Information Standard**
- NHS Education for Scotland's**Think Capacity, Think Consent (PDF)** – a learning resource supporting the application of the Adults with Incapacity Act (2000) in acute general hospitals.
- **Talking Mats** – picture-based communication system – see references for studies completed with talking mats.
- HCPC – **Guidance on consent principles**
- HCPC – **Guidance on consent and confidentiality**
- HCPC –**Video scenario on consent for students**

References

- **Adults with Incapacity (Scotland) Act** (2000)
- **Children Act, 1989 (Children)**
- Department of Health – **Reference guide to consent for examination of treatment** (2009)
- **Family Law Reform Act (1969) Section 8**
- General Medical Council – **Making and using visual and audio recordings of patients**
- **Human Rights Act, 1998 (Adults)** (2011)
- **Mental Capacity Act (2005)**
- **Mental Capacity Act (Northern Ireland)** (2016)
- Murphy J et al – **Talking Mats and involvement in decision-making for people with dementia (PDF)** (2010)
- NHS England – **Accessible Information Standards** (2016)
- **NIHR – resources for stroke researchers**
- NSPCC – **A child's legal rights: Gillick competency and Fraser guidelines**
- United Nations – **Convention on the Rights of the Child**

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