# Guidance on Information Sharing

This guidance has been developed in response to common concerns and questions about information sharing expressed by professionals working across children's health, care and education services in the Midlands. Professionals across these services explained they faced barriers to effectively and easily sharing information, including a lack of clarity about why they should share information; individual and organisational nervousness and uncertainty about the law and what is permissible; confusion about how to draft an Information Sharing Agreement (ISA) due to the different templates, standards and sign-off processes; and questions about how to ensure data sharing is secure. All of this hinders joined-up, multi-agency data and places additional burdens on professionals.

It is vital that individuals and services have sufficient support and guidance to share data and information in a practical, transparent, and safe way. This guidance document seeks to provide clarity on the most common questions and the accompanying ISA template with suggested wording should reduce the burden on individuals when completing an ISA. Having one clear ISA Template which has been developed jointly and which will be used across teams will reduce confusion, bureaucracy and duplication which some professionals currently encounter when trying to request or share information.

This guidance document seeks to build professionals' confidence and willingness to share data related to children and young people, whilst continuing to meet the requirements of the Data Protection Act 2018 (DPA), UK GDPR, and other relevant legislation.

The guidance covers:

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## 1: Why Information Sharing Matters

> **"Data speaks louder than words and more eloquently describes the complexity faced by the disabled children and young people and families that we serve. Data will make those most vulnerable in our society more visible and will provide a robust foundation for service development and research"**
>
> *Dr Karen Horridge [BACD chair, data champion and Consultant Paediatrician (Disability)]*

> "As a parent carer… I know that **data is key, not just to being able to commission and plan well for our children and services at a local and national level but also to address some of the practical problems we have in getting consistent, timely and complete diagnoses. Without all that we cannot get better outcomes for our children and young people."**
>
> *Mary Busk, Senior Family Carer Advisor, LD and Autism Programme at NHS England*

Sharing information and data between areas and across teams is essential to truly understanding and meeting the needs of children and young people with Special Educational Needs and Disabilities (SEND) at individual, local and regional levels. Information sharing is vital to:

- **Joined-up and improved care for individual children and families –** Good information sharing allows more families to 'tell their story once' and to receive more coordinated and joined up care. It also makes it less likely any child will 'fall between the gaps'
- **Local and regional strategic planning**– Robust information from a range of sources underpins the development of effective strategies which understand and seek to meet the needs of the population (i.e. JSNAs, commissioning and ICB/ICP strategies)
- **The design and development of new services and pathways –** More fully understanding the experiences, needs and pathways of children and young people with SEND allows for more targeted commissioning and accurate resource allocation. For example, in Staffordshire, improved information sharing led to the development of a combined paediatric, orthopaedic and physiotherapy postural management clinic, in order to meet a gap which had been identified from shared data and to reduce the number of school days being missed by the children on their registers.

Collecting data from a range of sources also supports the development of robust business cases which can demonstrate, for example, the need for additional therapists or paediatric specialists

- **Service improvement-** Shared information can highlight areas of challenge which need to be addressed, and good practice which can be replicated to improve services. Shared data enables services to measure the effectiveness of interventions and support, which leads to a continuous cycle of improvement.
- **Prevention and earlier identification -** Information sharing enables the identification and targeted follow-up of children who are identified as having additional vulnerabilities, allowing proactive support to be provided at an earlier stage and before they reach crisis.
- **Protecting children and young people** – Robust information sharing is key to effective safeguarding arrangements and identifying risk for individual children and young people
- **Education Health and Care Plans** (EHCP)- At an individual level, effective information sharing supports the creation of meaningful and child-centred EHCPs
- **Closes knowledge 'blind spots' –** Information sharing fills in 'blind spots' in the knowledge any one service or area can have on their own. For example, it is nearly impossible to keep track of where equipment has gone in a system, whether equipment needs to be maintained, and what the outcomes are for children who receive equipment without robust data sharing arrangements being put in place because of the range of partners involved (including social care, therapies, schools, health services etc.) Likewise, many areas have some 'blind spots' in understanding how to support children with the most complex needs as relevant information will often sit across different services and different areas. A recent study found that sharing information and using aligned terms across services was a crucial factor in understanding and truly addressing the needs of children who are at risk of dying prematurely[1].

Ultimately then, information sharing is essential to **monitoring and achieving better outcomes for children and young people.** With an increased emphasis on integrated working across the country, good information sharing is now more important than ever.

An Information Sharing Agreement should help all partners to share information more easily by:

- Helping all parties be clear about their roles;
- Setting out the purpose of the information sharing;
- Clarifying what information is to be shared;
- Detailing what will happen to the information at each stage; and
- Agreeing standards across organisations

An ISA should also help you justify information sharing and demonstrate that you have been mindful of all compliance considerations. An ISA provides a framework to help you meet the requirements of data protection principles, and should be clear and easy to understand.

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[1] Horridge, K. *Variation in health care for children and young people with a disability*. 2018

## 2: Understanding information sharing, GDPR and other legal requirements

When we spoke to practitioners from services across the Midlands, the greatest barrier to information sharing was people's perceptions and confusion around what can and cannot be legally shared. This was of particular concern when it came to individual-level data.

Of course, it is important to understand and comply with all legal requirements around data sharing. Nevertheless, the law does permit information sharing about children's health and care under many circumstances and it is also important to feel confident and able to share information when it is permissible to do so and when doing so will benefit children and young people.

The section below seeks therefore to set out what is legally permissible, in line with the advice we have received from the Information Governance Alliance, from local IG leads, and from Data Protection legal experts. **However, this resource is not a substitution for legal advice and if any legal issues arise, specialist advice should be taken in relation to that particular situation. If you have any questions or concerns, you should seek advice from your organisation's Information Governance Lead and Data Protection Officer in the first instance.**

### Legal basis for information sharing

You may share data relating to children's health and care as long as you can demonstrate a compelling reason to do so in law. All health and care providers are subjected to the statutory duty under section 251B of the *Health and Social Care Act 2012* to share information about a patient for their direct care. This duty is subject to the common law duty of confidence and should be done in accordance with the the Data Protection Act 2018, and UK GDPR. For common law purposes, sharing information for direct care can be on the basis of 'implied consent.'

In addition to Common Law, the Data Protection Act 2018 imposes a number of obligations on organisations that process and share personal data. For processing to be lawful, conditions set out in certain schedules within the Act must be met. All processing of personal data must satisfy at least one condition in schedule 2 whilst processing of sensitive personal data must also satisfy a condition in schedule 3.

While consent is an option in both schedule 2 and schedule 3, it is not the only lawful basis which can be used and consent is not required if a different condition can be satisfied. If you are relying on consent as the lawful basis, you must consider the competence of the child to give their own consent and whether it is freely given. However, for data relating to children, other lawful bases may often be more appropriate, for example.:

**Under schedule 2:**

- ***The processing is necessary for the exercise of functions of a public nature exercised in the public interest by any person.***

**Under schedule 3:**

- ***The processing is necessary for medical purposes and is undertaken by***

***a) a health professional, or***

***b) a person who in the circumstances owes a duty of confidentiality which is equivalent to that which would arise if that person were a health professional.***

Section 204 of the Data Protection Act 2018 clarifies that 'health professional' includes a wide range of health and care professionals, including child psychotherapists, occupational therapists, speech and language therapists and social workers. Please see Section 204 for more information. 'Medical purposes' includes the purposes of preventative medicine, medical diagnosis, medical research, the provision of care and the management of healthcare services. The Information Commissioner has confirmed that the definition of medical purposes is broad enough to cover care in its wider sense, and can include social care.

The Information Governance Review similarly explained that the definition of direct care in the context of information sharing "**includes supporting individuals' ability to function and improve the participation in life and society. It includes the assurance of safe and high-quality care."** This confirms a permissive basis for sharing children's data for the above purposes.

Under UK GDPR, to lawfully share personal data, you must identify an Article 6 condition. The most relevant Article 6 conditions for lawful processing that are available to all publicly funded health and/or statutory health and social organisations in the delivery of their functions are:

> **6(1)(c)** ***Processing is necessary for compliance with a legal obligation to which the controller is subject***
> or
> **6(1)(e*****) Public task: the processing is necessary for you to perform a task in the public interest or in your official functions, and the task or function has a clear basis in law.***

Special category data can only be processed or shared if you can also meet one of the conditions in Article 9 of the UK GDPR. Explicit consent is a condition under Article 9(2)(a) but the most relevant Article 9 conditions is likely:

> **9(2)(h) Health or social care -** ***Processing is necessary for the purposes of preventive or occupational medicine, for the assessment of the working capacity of the employee, medical diagnosis, the provision of health or social care or treatment of the management of health and social care systems and services on the basis of Union or Member State law or pursuant to contract with a health professional and subject to the conditions and safeguards referred to in paragraph 3.***

It is worth noting that an NHS number does not in itself constitute a special category of personal data, as it would not in and of itself give access to clinical data associated with the number. The most appropriate legal basis under GDPR would be 6(1)e *Performance of a task carried out in the public interest or in the exercise of official authority vested in the controller*. This is the basis on which the NHS number is already shared in many health and social care settings as a robust common identifier, including pre-school and school services.

### Additional legal justifications

Depending on the purpose of the ISA, additional wording and legal justification may be included in an ISA. Example wording is offered below:

- For information related to the creation of EHCPs:
  *"Partners are required to share information for creating and reviewing EHCPs, as per Part 3 of the Children and Families Act 2014."*

- For information related to child protection:
  *"Section 47(1) of the Children Act 1989 states that: Where a local authority:*
  *(a) is informed that a child who lives, or is found, in their area (i) is the subject of an emergency protection order, or (ii) is in police protection and*
  *(b) have reasonable cause to suspect that a child who lives, or is found, in their area is suffering, or is likely to suffer, significant harm:*
  *the authority shall make, or cause to be made, such enquires as they consider necessary to enable them to decide whether they should take any action to safeguard and promote the child's welfare."*

- For Children's Centres:
  The Government has published the "Core Purpose" of Children's Centres which includes *"working in partnership across professional/agency boundaries to support improving outcomes for young children and their families, and reducing inequalities."*
  The Sure Start Children's Centres Statutory Guidance, published in 2013, stated "*Families are able to access all the early childhood services they need through children's centres. This means working in an integrated way with other services to share information appropriately and identify the families in greatest need*."

## 3: How to ensure data is secure

The ISA template prompts partners sharing data to consider how to share, use and store information in secure ways. Some additional examples are given below:

### *Sharing data*

Information must be shared in a secure way, such as:

- via a secure web portal
- via an industry standard secure email e.g.  .nhs.net
- via encrypted files with industry standard security
- confirmed delivery post (if agreed in advance)

### *Storing data*

Information must be stored in a secure environment where the information is protected and access to it is controlled and restricted. You will likely already have Data Security Policies which dictate how this should be done in your service, for example a requirement to stall all data on a secure SQL server, and/or in password protected files which can only be accessed by select staff directly working on a particular programme.

Services should also provide training for their staff on data security and have sanctions in place for breaches by individual staff.

### *When to undertake a Data Protection Impact Assessment (DPIA)*

A Data Protection Impact Assessment (DPIA) is a process to help individuals and organisations identify and minimise data protection risks for data sharing and processing projects which are particularly 'high risk.'

It is a legal requirement to complete a DPIA for any data processing which is likely to result in a high risk to individuals. The Information Commissioner's Office (ICO) has published a checklist to help you decide when to do a DPIA. According to the ICO, you **should** carry out a DPIA if you plan to:

- use systematic and extensive profiling or automated decision-making to make significant decisions about people;
- process special-category data or criminal-offence data on a large scale;
- systematically monitor a publicly accessible place on a large scale;
- use profiling, automated decision-making or special category data to help make decisions on someone's access to a service, opportunity or benefit;
- carry out profiling on a large scale;
- process personal data without providing a privacy notice directly to the individual in combination with any of the criteria in the European guidelines;
- process children's personal data for profiling and/or for marketing purposes;
- process personal data that could result in a risk of physical harm in the event of a security breach

However, **you may also wish to complete a DPIA for any project that will process significant special category data** to help you assess and minimise risk. You should consult your organisation's Data Protection Officer if you have any questions or concerns and to help you understand data processing activities and their associated risks.

**A DPIA is undertaken in addition to an Information Sharing Agreement but some sections are shared between them.** Like an ISA, a DPIA should describe the nature, scope and purposes of processing and sharing data and assess adherence to compliance measures. In addition, it must identify and assess risks to individuals of the data sharing and identify additional measures being taken to mitigate those risks. The ICO has a template DPIA which can be accessed here and additional resources which can be accessed here.

## 4: Aligning language and coding data

### Importance of using common language and terminologies

Definitions and terminology can vary between services and areas which can lead to confusion about what information is to be shared (for example where there are significant differences between what is meant by 'place based') as well as leading to incomplete data sets which miss out important information because it has been labelled differently to what was expected. Colleagues across the Midlands highlighted this as a key barrier to effective information sharing.

It is therefore crucial than when developing an Information Sharing Agreement, each party establish that they have a common understanding about the terms being used throughout and that they align their language and their data terminologies. It is also important to use precise language, rather than vague or all encompassing terms.

### Advice on using SNOMED CT codes and language

#### *What is SNOMED CT*

The NHS is signed up to a terminology framework, SNOMED Clinical Terms (CT) which was developed by a range multi-agency partners in order to establish consistent terms and data coding across health. While its use is not currently mandatory, using SNOMED Clinical Terms (CT) can support the harmonisation of terms between different teams and services and enables more streamlined information sharing and analysis about children's health and care, and SNOMED CT codes are used across the Midlands. SNOMED CT is a systematically organised collection of medical and care terms providing codes, terms, and definitions used for clinical documenting and reporting. Essentially, **SNOMED CT provides a single vocabulary to describe the multifaceted needs and experiences of disabled children** to ensure everyone uses the same labels to describe the same thing, and that terms are interpreted in the same way across services and specialisms.

#### *SNOMED CT and SEND*

Paediatricians and community child health experts worked together with therapists from the British Academy of Childhood Disability, along with parents and terminologists to develop **a comprehensive Paediatric Disabilities Terminology subset**. The subset has been designed to fit the different stages of the journey for children and families, from initial presentation when concepts needed to be broad (e.g. 'impaired social interaction') through to specific terms and detail which results from subsequent assessment, investigation or intervention (e.g. 'autism spectrum disorder').

The British Academy of Childhood Disability (BACD) and other partners have now produced **an** Explanatory Glossary **which sits alongside the SNOMED Paediatric Disabilities subset**. This explanatory glossary **clearly explains each term and gives additional guidance on SMOMED CT use**, to encourage consistent use of the same terms across services and areas. Adopting this consistent approach across an Information Sharing Partnership can be incredibly useful, particularly if it involves a number of different healthcare providers.

Whilst thousands of terms are included in the current SNOMED CT set, and there are hundreds of disability specific terms included, this work is currently being significantly expanded by paediatricians, terminologists, clinicians, parent carers and other stakeholders in order to encompass even more specialisms.

### *What are the benefits of using SNOMED CT when sharing information*

- **Information can be shared consistently** within and across health and care settings
- There is a **reduced risk of misinterpretation** of information across different settings. This reduction in ambiguity also **facilitates data analysis**
- SNOMED CT allows **great depth of details** across clinical specialities. It goes beyond recording health conditions or formal diagnosis: **body structures, function, activities, family issues, technology dependencies and needs are all covered**
- Because SNOMED is hierarchical, different levels of detail can be captured which are relevant for different purposes or settings. For example, a child may be recorded as having spastic cerebral palsy → cerebral palsy → physical disability, allowing **different levels of detail to be looked at, without double counting any individual child in the system.** It is also a simple way to capture multiple and overlapping needs experienced by children with disabilities or special educational needs
- **Data can be collected once and then used for many different purposes** due to the hierarchical structure of coding
- Because the terms were agreed via a multi-agency and coproduced process, outdated or offensive terms were removed
- Having data appropriately labelled when it is shared is essential to the Commissioning for Quality and Innovation framework, and more generally underpins **effective commissioning, service design and service delivery**

### Further resources on understanding and using SNOMED CT

- BACD: Explanatory Glossary of Paediatric Disability Terms
- RCPCH: How to guide for SNOMED

# 5: Completing an Information Sharing Agreement

## Information Sharing Agreement Template

The Information Sharing Agreement will be linked and attached as an Appendix. The ISA Template contains guidance, but if you would like further guidance on how to complete the ISA please read below or contact your IG Lead.

## Using the Information Sharing Agreement Template

The text in green on the template is standard wording that it is recommended to include in the agreement, although you can amend the language to suit the sharing parties if you so wish.  Examples are provided in blue text. For more detail, see below:

**Section 1: Partners/Parties/Signatories** - This is self-explanatory but you should list all of the parties to the agreement.

**Section 2: Purpose** – Explain why the data sharing is needed and what benefits the information sharing will bring. You need to include the primary purposes of the data as well as any secondary uses e.g. planning, commissioning and research

**Section 3: What is the legal basis?** - This can be a complex area to understand and if you have further questions or concerns after consulting this guidance and the template, you are recommended to seek advice from your local Information Governance Lead. Where a Data Protection Impact Assessment has been completed it is likely that this has already been determined and therefore you can include information from the DPIA in the agreement.

**Section 4: What information is to be shared? - T**his is self-explanatory and you should include details of what will be shared in the most suitable format. You could add a table, a data flow picture, a list– whatever works best.

**Section 5: What will the data be used for?** – Explain what the data will be used for. You need to include the primary purposes of the data as well as any secondary uses e.g. planning, commissioning and research

**Section 6: Controllers** – This is really important. You should identify the role of each party to the agreement so that they are clear as to their obligations under the Data Protection Legislation. Advice should always be taken to identify the correct role if in any doubt, as there are legal obligations to be taken into account. There are some standard clauses set out in the template that should be included to emphasise responsibility for aspects of the agreement.

**Section 7: Who will have access?** Statements are included which are standard but you can be explicit if it suits the sharing situation better.

**Section 8: How will accuracy of information be maintained?** – Statements are included which are standard but you can be explicit about the steps you will take to ensure information is accurate if that suits the sharing situation better.

**Section 9: How will information be kept secure?** Statements are included which are standard, but you need to add additional detail of how you will ensure the information remains secure and where it will be stored in each organisation. You must detail if any data is being transferred outside of the UK (this is to ensure compliance with Article 45 of the UK GDPR). You should include a link to a DPIA if that has been undertaken.

**Section 10: How long will the information be kept?** – Include what has been agreed between the parties.

**Section 11: How will data be disposed of?** Explain how the data will be disposed of in a secure way and how this will be evidenced.

**Section 12: Further Obligations** – This section includes a number of standard statements that can be found in many information sharing agreements. They remind the parties of their obligations as a sharing party but they can be added to/removed/amended according to the needs of the agreement.

**Section 13 - 19** – These sections are self-explanatory and contain standard causes that are common to many agreements where a number of organisations have responsibilities being shared.

## Glossary of key terms

Caldicott Guardian **-** A senior person responsible for protecting the confidentiality of patient or service-user's health and care information and for enabling appropriate information-sharing within the law. All NHS organisations and local authorities which provide social services will have a Caldicott Guardian. According to UKCGC guidance, a Caldicott Guardian should ideally be an existing member of senior management, a senior health or social care professional, and the personal responsible for promoting clinical governance. Caldicott Guardians should also provide leadership and guidance on complex matters relating to information sharing. For more information please see the UK Caldicott Guardian Council (UKCGC) website.

Data Controller - A person or organisation who (either alone or jointly) determines the way in which personal data is to be processed and the purposes for which any personal data is to be processed. Data controllers are the main decision-makers and are subject to a number of requirements under data protection law; data processors act on behalf of the data controller.

Data Processor - Any person (excluding an employee of the data controller) who processes the data *on behalf of the data controller*. Processing data includes everything done with data or information i.e. obtaining, storing, analysing, using, sharing or disposing of data.

Data Processing Agreement (DPA) – DPAs are used when the Data Controller asks another party to *process* data on their behalf (in a similar way to how ISAs are used when *sharing* data). For example, a GP practice might ask their GP Federation to store data on their behalf - they are not sharing data with the GP Federation, the GP Federation are processing data on their behalf and under their instruction. DPAs are legally binding agreements.

Data Protection Officer (DPO)– Any health or social care organisations which are public bodies (including NHS Trusts, health commissioners, local authorities and arm's length bodies) must appoint a Data Protection Officer (DPO) if they process or share data. The DPO plays a key role in facilitating appropriate data sharing and demonstrating compliance with GDPR and other legislation. The DPO should be independent from the organisation's management, unlike the Caldicott Guardian, and their focus is often broader than patient data.

Data Protection Impact Assessment (DPIA) – A DPIA is a process to help individuals and organisations identify and minimise data protection risks of a project. There is a legal requirement to complete a DPIA for data processing or sharing that is likely to result in a high risk to individuals. DPIAs are completed in addition to an Information Sharing Agreement but feature much of the same information.

Information Governance (IG) Lead – A representative from senior management who is appointed as a 'champion' on data sharing and processing and to coordinate information governance work. The IG Lead is accountable for ensuring effective management, accountability and compliance for all aspects of information governance. In small organisations, the individual might also take on responsibilities of either the Caldicott Guardian function or the Data Protection Officer.

Information Sharing Agreement (ISA) – ISAs are used when two or more services or data controllers *share* data. They are not a statutory requirement but they are a useful mechanism to ensure secure and lawful data sharing. ISAs facilitate the sharing of data, including confidential data, by setting out governance mechanisms and supporting each party to come to an agreement about their expectations of each other. ISAs should show you have considered all necessary components involved in sharing data.

In this context, information and data are often used interchangeably, so an ISA might also be referred to as a Data Sharing Agreement (DSA) or a Data Sharing Protocol (DSP).

Special category of data – Special category data is sensitive, personal data. It is defined in Article 9.1 of the UK GDPR as personal data which reveals racial or ethnic origin; political opinions; religious or philosophical beliefs; trade union membership; genetic data and biometric data used for the purpose of uniquely identifying a person; data concerning health; and data concerning a person's sex life or sexual orientation. The processing of this type of data needs greater protection. To lawfully share or process any type of data, you must identify an Article 6 basis for processing or sharing. Special category data can only be processed or shared if you can also meet one of the conditions in Article 9 of the UK GDPR. Article 9 conditions for processing special category data include, but are not limited to, health or social care purposes; public health purposes; and explicit consent. You are also more likely to need to do a DPIA for processing or sharing special category data. For more information, see the UK Information Commissioner's guidance on special category data.

## Further resources:

If you have any specific questions, please contact your organisation's IG Lead or Caldicott Guardian in the first instance. You can also find more guidance on information sharing at the sources below:

- Information Commissioner's Office, *Data sharing code of practice* (2020) https://ico.org.uk/media/for-organisations/guide-to-data-protection/ico-codes-of-practice/data-sharing-a-code-of-practice-1-0.pdf
- Information Commissioner's Officer, *DPIA Guidance* (2020) https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/accountability-and-governance/data-protection-impact-assessments/
- Department for Health and Social Care, *Data saves lives: reshaping health and social care with data* (2021) https://www.gov.uk/government/publications/data-saves-lives-reshaping-health-and-social-care-with-data-draft/data-saves-lives-reshaping-health-and-social-care-with-data-draft
- Council for Disabled Children, *SEND Data Bulletins*, *https://councilfordisabledchildren.org.uk/resources/all-resources/filter/health/send-data-bulletins*