**Plain English Guide to Information Sharing**

[Ripple Community Programme](http://www.rippleosi.org/)

Guidance to accompany the Information Sharing Agreement for Direct Care Template

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Contents

[1. Introduction 3](#_Toc426375951)

[2. Purpose of this guidance 3](#_Toc426375952)

[3. Audience 4](#_Toc426375953)

[4. Background 4](#_Toc426375954)

[5. Prerequisites 5](#_Toc426375955)

[6. Compliance with the Information Commissioner’s Data Sharing Code of Practice. 5](#_Toc426375956)

[7. Purpose of the data sharing initiative 6](#_Toc426375957)

[8. Who is involved in the Information Sharing Agreement? 6](#_Toc426375958)

[9. What Information is being shared? 7](#_Toc426375959)

[10. Why is information shared? 8](#_Toc426375960)

[11. When is information shared? 9](#_Toc426375961)

[12. Where information is shared 9](#_Toc426375962)

[13. How information is shared (the legal basis for sharing) 10](#_Toc426375963)

[14. Information Governance 14](#_Toc426375964)

[15. Signatories 15](#_Toc426375965)

[16. Glossary 16](#_Toc426375966)

# Introduction

As we move Health and Social Care into the 21st Century, the need to improve care underpinned by better information sharing is paramount. For many health and social care professionals’ efforts around “information sharing” have become a real challenge. Central to that challenge has been the growing confusion about good practice in information governance, particularly when it comes to information sharing.  Our experience is that even the language is this field has become so overly complicated that is has become a barrier to progress in its own right.

With that in mind we wanted to delve deep into what is at issue here by looking for some simple patterns to make this area a whole lot simpler, in essence a Plain English guide to Information Sharing. As we begin to explain our latest thinking on this, we want to give due credit to Joseph Waller director of [XML Solutions](http://www.xml-solutions.com/) whose “[proposed consent model](http://www.xml-solutions.com/a-proposed-consent-model/)” we have deliberately reviewed, reused and hopefully improved.

To explain our **Plain English guide to Information Sharing**, we wanted to try a Who, Where, What, Why, When and How approach. We think it’s been fairly helpful.

# Purpose of this guidance

As part of the Ripple programme, we have developed our **Plain English Guide to Information Sharing** to explain how the Information Sharing Agreement template should be developed for local needs. The **guidance** provides supporting information to assist organisations to use the template for their own purpose and a glossary to explain words highlighted throughout the document. You are free to amend the template to suit your particular needs. Note: this Information Sharing Agreement does not cover the purpose of indirect care (e.g. research) although it is expected this will be addressed as part of the Ripple programme shortly.

To explain information sharing we have used a **Who, Where, What, Why, When and How** approach and have structured this Information Sharing Agreement in that way.

We want to give due credit to Joseph Waller director of XML Solutions, whose “[proposed consent model](http://www.xml-solutions.com/a-proposed-consent-model/)” of **implied, supplied, denied override**, we have deliberately reviewed, reused and hopefully improved.

In addition to the[**Plain English Guide to Information Sharing**](http://rippleosi.org/resources-2/information-sharing-explained/) **and Information Sharing Agreement template,** the Ripple programme has also developed a **Plain English Data Controller Contract**, which is also available for adaptation for local use.

# Audience

The intended audience for this guidance is anyone working in a health or adult social care commissioner or provider organisation who is responsible for establishing information sharing arrangements.

They do not need to be Information Governance experts. They may however wish to seek help from Information Governance experts to agree the content and use of the Plain English Information Sharing Agreement and/or Data Controller contract templates according to local needs.

# Background

The safe, secure and legitimate handling of information is at the very core of health and social care.  As we move Health and Social Care into the 21st Century, the need to improve care underpinned by better information sharing is paramount.

Health and social care organisations are working in partnership to ensure local services are integrated and meet the needs of individuals within the local population. Health and social care professionals’ access to information at the right time, in the right place and within the right health and social care setting means that individuals are treated more safely and effectively.

Even though it is in the best interests of the individual concerned to do so, any use or sharing of a person’s information has to be done in respect of their right to confidentiality and in a way that is lawful. Information should also meet standards to ensure it is of good quality and securely protected.

Each organisation involved in the Information Sharing Agreement is individually responsible for making sure their staff know how to handle confidential information and individuals using their services are told how their information is being used and are offered some control over the way it is used.

The Health and Social Care (Safety and Quality) Act 2015 becomes effective in October 2015. This piece of legislation is a significant for information sharing because it puts the 7thCaldicott Principle – the duty to share information is as important as the duty to protect confidential information - onto a legal footing. It operates on the presumption that information supporting the delivery of care to the individual should be shared, unless they object.

We have based this guidance on the presumption that information that supports the delivery of care to the individual should be shared, unless they object, however, we need to be mindful that details about the correct interpretation of the Act will come with the DH guidance and this guidance will need to be updated accordingly.

The Information Sharing Agreement Template

# Prerequisites

The Information Sharing Agreement works on a prerequisite that the health and social care organisations involved in information sharing for direct care purposes, know they are Data Controllers in terms of the Data Protection Act 1998 (DPA) and therefore legally responsible for ensuring their organisation and staff handle personal confidential data fairly and in accordance with the relevant laws.

In addition to their legal responsibilities, providers of health and social care services also have contractual obligations to comply with the law and protect individual service users confidentiality.

They are also required to complete an annual self-assessment of their standards of practice using the Department of Health’s Information Governance Toolkit.

They are liable if things go wrong and personal data is lost or misused. They are directly accountable to the Information Commissioner and risk enforcement action for a breach of the DPA and they could also be sued by the individual whose personal data has been compromised. Contractual penalties may also be applied.

Information sharing arrangements should be agreed between trusted partners without the need to spell out these responsibilities or set clauses to hold each other to account. This is why the Information Sharing Governance template does not include specific reference or impose requirements on the data controller partners.

Organisations may add such clauses if they feel it is necessary.

# Compliance with the Information Commissioner’s Data Sharing Code of Practice.

The ICO’s Data sharing code of practice includes guidance on the development of Information Sharing Agreements (Data Sharing Agreements chapter 14).

<https://ico.org.uk/media/for-organisations/documents/1068/data_sharing_code_of_practice.pdf>

The Plain English Information Sharing Agreement “**Who, what, why, when, where and how**” structure was mapped over to both the ICO code of practice to make sure it conformed to recommended good practice. We think that with a bit of adaptation it does.

The Information Sharing Agreement Chapters

# Purpose of the data sharing initiative

**ISA Template Section 1.**

The Information Sharing Agreement should satisfy three purposes:

* A documented agreement between the health and social care organisations;
* Guidance for staff who will be sharing information; and
* An explanation to service users, which has additional information to fair processing materials.

The wording should therefore be clear and understandable for all audiences – use plain English and avoid abbreviations.

This section of the Information Sharing Agreement should explain why the information sharing is necessary.

# Who is involved in the Information Sharing Agreement?

**ISA Template Section 2**

“**Who**” means who are those involved in information sharing – who is it about and who is receiving the information?

The **individual** who, in times of need seeks help from a health or social care professional is the central focus of the Information Sharing Agreement.

An individual has certain rights regarding their personal information, including a right to access that information and a right to object to it being used in certain ways. Respecting the individual’s expectations about confidentiality and security, and telling them how and why their personal information is used should be a key principle of the information sharing agreement.

“**Who**” includes who the information is shared with.

For direct care this will include all of the health and social care workers who work together in teams responsible for coordinating and providing care and treatment to the individual according to their need. For example:

* GP and GP Practice staff;
* specialist doctors such as a hospital consultant and their clinical team;
* nurses and midwives;
* physio and other therapists;
* radiology and laboratory staff processing test results;
* pharmacists;
* social care staff;
* staff supporting the team such as administrative staff who book appointments, make sure paper records or other relevant information is available at the point of care, write letters, greet people at clinics, receive telephone calls and other supporting tasks;

It may not be obvious to the individual that staff working behind the scenes i.e. the ones that they will not come into contact with will have access to their personal data as well as those they see on a regular basis. It is important to make it clear in the ISA **who** is included when explaining information sharing. This transparency and openness adds value to the fair processing principles that is supporting the implied consent basis for sharing.

These professionals may be from public, non-government or voluntary service organisations. Whoever is using information about a person is bound by laws, contracts and professional codes of conduct to use it responsibly and keep it confidential.

The agreement should clearly identify all of the organisations involved in the information sharing arrangement. Schedule 1 in the template provides an organisational list.

You may wish to include local procedures for adding new organisations, excluding or terminating an organisation and details about the governing body overseeing the agreement.

# What Information is being shared?

**ISA Template Section 3**

People cannot be treated or cared for safely if health and social care professionals do not have access to information about them.

All information about an identifiable person and their physical and mental health and condition is **confidential.**  Relevant information about the person and their current care needs will only be shared by the health and social care professionals who are involved in the provision of care and treatment to the individual (the “**direct care team**”) when it is:

1. necessary for them to be able to do their job; and
2. with the person’s knowledge and agreement; and
3. in accordance with the conditions set out in law.

Relevant information about the person and their current care needs should be shared by the health and social care professionals who are involved in the provision of care and treatment to the individual (the “**direct care team**”).

“Relevant information” is information that may directly influence the health or social care professionals’ decision about what care is given to a patient or service user, and how that care should be given (*Independent Information Governance Review/Caldicott 2*). It is not necessary for everybody to know everything. Some information will be relevant to certain professional groups but completely irrelevant to others and therefore should not be shared.

The amount of personal information that needs to be shared to support care will therefore vary on a case by case basis.

The presumption is that information will be shared to support an individual’s direct care unless they object.

Excluded information

Some information is particularly personal sensitive information (e.g. HIV status, sexual health in The NHS (Venereal Diseases) Regulations 1974, The NHS Trusts (Venereal Diseases) Directions 1991 and The NHS Trusts and Primary Care Trusts (Sexually Transmitted Diseases) Directions 2000; Human Fertilisation and Embryology Act 1990, Gender Recognition Act 2004) and its use is strictly controlled by law. The sharing of this type of information is excluded from this Information Sharing Agreement.

The presumption is that information will be shared to support an individual’s direct care unless they object.

The Information Sharing Agreement should explain the types of data being shared and exclusions. Schedule 2 in the template provides an example table for this purpose.

# Why is information shared?

**ISA Template Section 4**

This section justifies why information listed in Section 2 is being shared.

For example:

Information is shared:

1. to support the **direct care**of the individual (e.g. a patient attending their GP or local Emergency Department, or are being cared for by a team of district nurses or a team of various health and social care professionals who could be from different organisations; or
2. to assess the quality and safety of care being provided

# When is information shared?

**ISA Template Section 5**

Information will only be shared when it is fair and lawful to do so.  There are legal and ethical rules of confidentiality and privacy which mean that individual’s rights have to be respected.

When the individual agrees to being treated it creates a direct care relationship between them and the health or social care professionals in the direct care team. This is known as a “legitimate relationship”.

The Health and Social Care (Safety and Quality) Act 2015, which is due to be enacted in October 2015, will introduce a legal duty to share information when:

1. It will facilitate the provision of health and social care services to the individual; and
2. It is in the individual’s best interest; and
3. The individual has not objected.

This Act puts the 7thCaldicott principle – the duty to share information can be as important as the duty to protect confidentiality - onto a legal footing.

The presumption is that information can be shared unless the patient objects.

The Department of Health are developing guidance to support the implementation of the Act. This section will therefore need to be reviewed and updated in line with that guidance when available.

# Where information is shared

**ISA Template Section 6**

By **where** we mean the location or setting where the person sees a health or social care professional. For example:

**Providers of health and social care, including**

* Primary care setting e.g. GP Practice,
* Community care e.g. at home, a community hospital, care home, day centre or hospice;
* Secondary care e.g. hospital appointment or admission, or Emergency Department;
* Tertiary care setting (specialist)
* Mental Health services – various locations e.g. hospital, clinic, centres
* Some third sector community support settings.

Or other locations where the information is shared but the individual is not present, for example:

1. Offices where clerical and secretarial staff carry out administrative functions that support direct care and the direct care team;
2. Laboratories processing test results
3. Any other local example

# How information is shared (the legal basis for sharing)

**ISA Template Section 7**

Whilst the Health and Social Care (Safety and Quality) Act 2015 brings in a duty to share information, consideration still has to be given to the application of the DPA and Common Law Duty of Confidence.

Information should only be shared in accordance with the law and with respect for the rights and wishes of the individual whose personal confidential data it is.

All of the partner organisations involved will follow the laws that control the use of confidential information i.e.

* The Common Law Duty of Confidence;
* The Data Protection Act 1998 (DPA); and
* The Human Rights Act 1998 (HRA).

All health and social care organisations must operate and use personal confidential data within this legal framework. They are individually responsible for ensuring that they have established good information governance practice and have trained their staff so that information is appropriately managed, of high quality and individual’s rights are respected.

**The Common Law Duty of Confidence**

The Common Law Duty of Confidence applies to information given “in the expectation of confidence (doctor/patient relationship) and that which is “owed a duty of confidence” (we all owe a duty of confidence when using personal data). Information given in confidence for one purpose should not be used for another purpose without a legal basis such as consent, where it is required or permitted by statute, where the public interest outweighs the individual’s right to confidentiality or, when it is required by a court order.

State which common law duty of confidence basis that applies to your local information sharing arrangement here.

**The Data Protection Act 1998**

The Data Protection Act applies to personal data and sensitive personal data, both of which have specific definitions in section 1 of the Act. The Act balances the rights of the individual with the legitimate business purposes of the organisation using it through a framework of 8 principles.

The organisation, as the “Data Controller”, is legally responsible for making sure their use of personal data complies with the data protection principles. The First Principle of the Data Protection Act requires personal data are processed (used) “fairly and lawfully”. This means that the organisation is responsible for making sure that the purposes for use are transparent and not outside reasonable expectations of the individual who is the subject of the personal data, and must not cause unwarranted detriment. The common law duty of confidence and other relevant laws must be respected.

The First Principle also requires that any use of personal data meets one of the conditions set out in Schedule 2 of the Act. Any use of sensitive personal data has to meet a condition set out in both Schedule 2 and Schedule 3.

The Schedule 2 and Schedule 3 condition that apply to information sharing for health care purposes are:

Data Protection Act 1998 Schedule 2 Section 5(c) – the processing is necessary for the exercise of any functions of a government department.

Data Protection Act 1998 Schedule 3 Section 8(1) 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.

Medical purposes is defined as “preventative medicine, medical diagnosis, medical research, the provision of care and treatment and the management of healthcare services”.

The Department of Health guidance on the Health and Social Care (Safety and Quality) Act 2015 when published is expected to confirm the Schedule 2 and Schedule 3 conditions under which both health and social care services can lawfully operate.

Local adaptation of the Information Sharing Agreement should specify what Schedule 2 and Schedule 3 conditions apply.

**The Human Rights Act 1998**

The Human Rights Act 1998 applies to UK public authorities, also private sector organisations when they carry out activities of a public nature.

Article 8 gives everyone the right to “respect for his private and family life, his home and his correspondence”. The right is not absolute, but any interference with the right by a public authority must be in accordance with the law, and be necessary for example for the prevention of crime, or protection of health.

These statutory instruments control the use of personal data and provide an individual with a right of choice.

* The common law duty of confidence provides a right of choice through its basis of consent;
* The Data Protection Act 1998 (DPA) provides a right to object to, or stop the use of personal data;
* The Human Rights Act 1998 (HRA) provides a right to a private life including the right to have medical information kept private and confidential and self-determination over such private information.

**Fair Processing**

A fundamental requirement underpinning this Information Sharing Agreement is that all organisations operate within “fair processing” principles. This is where the health and care organisations involved communicate as widely as they reasonably can to tell people how information about them will be used and shared between professionals when it is “fair and lawful” to do so.

Fair processing means the individual understands how their information is being used, who it is being shared with, what is being shared for and why. They also need to understand that they have a right to ask that certain information about them is not shared (object) and what they need to do/ who they should contact to register their objection.

Actively telling people how their personal confidential information will be used and shared by the health and social care professionals who are looking after the individual will allow the direct care team to assume they have **implied** consent as part of the individual’s consent to receive care and treatment unless the individual **objects.** This will support their legal duty to share information under the Health and Social Care (Safety & Quality) Act when it comes into force.

There are rare occasions, such as the wider public safety or individual safeguarding issues where this right to object can be **overridden** but at all times and on all occasions, this has to be explained to the individual concerned on a case-by-case basis as it arises.

This section should be used to describe the local fair processing arrangements that support the Information Sharing Agreement.

* **Implied**

To support integration of services, information needs to be shared between health and social care professionals more widely so people can do their jobs as effectively as possibleto improve care. In the majority of cases, consent to information sharing for direct care is simply **implied** as part of the individual’s consent to receive care and treatment as long as they have been provided with fair processing information to explain this.

Unless informed otherwise, the general assumption is that people are happy for their information to be shared for a direct care purpose.

Explain to what extent your information sharing will be relying on implied consent.

* **Supplied**

A health or social care professional may decide to make a verbal or written **request** to ask the individual for permission to share their personal confidential information. For example, they may wish to share information with a professional who is not a current member of the direct care team or from a health or social care provider who is not mentioned in the fair processing information.

The individual can respond by either agreeing to **supply** consent to share their information (which is by far the most common response) or, **deny**consent for the information sharing request (which is only done occasionally, but is technically explained as a refusal or **objection** to share information).

Where it is necessary to get permission because there is no other legal basis to use personal confidential data for a specific purpose, but permission has not be **supplied** or it has been **denied**, then you cannot use or share information for that purpose.

Provide local examples of when permission to share will be requested or state if not applicable with rationale.

* **Denied**

The **NHS Constitution** states that an individual has the right to **object** to information about them being shared in a form that might identify them and in general to have reasonable objections to this sharing upheld. This is a broad statement that reflects the more complex legal framework:

* The common law duty of confidence, which provides a right of choice through its basis of consent;
* The Data Protection Act 1998, which provides a right to object to, or stop the use of personal data;
* The Human Rights Act 1998, which provides a right to a private life including the right to have medical information kept private and confidential and self-determination over such private information.

On rare occasions an individual may express a concern or object to information about them being shared for direct care. If this happens, a relevant health or care professional should make it clear to the individual that their decision may compromise their ability to provide safe and adequate care. Alternative options should be discussed and agreed with them. Explain those local procedures in this section.

An individual’s objection is managed by their registered GP Practice who are responsible for allocating a clinical code appropriate to the objection to the GP Record.

The right to object and how an individual registers an objection should be included in the fair processing information published by all partner organisations.

A local Patient Consent and Objections Management policy is recommended to support the Information Sharing Agreement to ensure all partners are dealing with individual choices consistently.

Provide an explanation as to how objections will be managed.

* **Override**

If a patient lacks the **capacity** to make a decision, the health or social care professional can **override** the requirement for consent and access or share confidential information they believe is required to provide essential care and treatment and in the person’s best interest. This is also known as “breaking the glass”.

A health or social care professional can also **override** a person’s objection in the following situations:

* By law doctors have to share information with Public Health when a patient with a “notifiable disease” is identified.  This helps to control the spread of infection and protects the public.
* Information should be shared when it is necessary to protect a child or vulnerable adult from harm.
* Various regulatory bodies have statutory powers to access patients’ records as part of their duties to investigate complaints, accidents or a health or social care professionals’ fitness to practise.
* Where a judge issues a court order for the disclosure of information; or
* There is a significant public interest in the sharing of information that is greater than the combined public interest in the provision of confidential services and the individual’s right to confidentiality. For example, the public interest would support the sharing of information about an individual who is not medically fit to drive but refuses to stop, or to protect another individual against a direct risk to their health. This has to be considered on a case by case basis.
* Etc*. [add local arrangements here]*

# Information Governance

**ISA Template Section 8.**

Section 8 is pre-populated with 8 information governance statements. These can be added to, amended, included in the signatory section etc. – adapt the template to your local preferences.

It should however be noted that the Information Commissioner’s Data Sharing Code of Practice (section 14 Data Sharing Agreements) does include a section on Information Governance, which is why this section is included.

# Signatories

This ISA should be signed by a senior member of the organisation who would be able to take ultimate responsibility if something should go wrong. This may be the Chief Executive, Caldicott Guardian, Chief Technical Officer, Director, Senior Responsible Owner, Senior Information Risk Owner, or someone with similar responsibilities. The person who signs the contract will be ultimately responsible for ensuring that the terms are met and that the data is only processed and used within the limits of the agreement.

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# Glossary

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| **Term** | **Description** |
| **Capacity** | All adults are presumed to have sufficient capacity to make a decision unless there is sufficient evidence to suggest otherwise. Capacity means the ability to understand, retain and use information to make a decision and to communicate that decision. |
| **Consent/Informed consent** | The approval or agreement for something to happen after consideration. For consent to be legally valid individuals should know and understand how their information is to be used and shared (there should be ‘no surprises’) and they should understand the implications of their decision, particularly where refusing to allow information to be shared is likely to affect the care they receive. |
| * **Implied** | Implied consent is applicable only within the context of direct care of individuals. Having been informed, consent to the sharing of information is part of consent to receive health and care can be assumed if they have not objected. |
| * **Supplied** | Explicit consent is provided when the individual has been informed about the intended information sharing and been asked for their permission. |
| * **Denied** | Having been informed about the intended information sharing purpose the individual has refused permission. |
| * **Override** | In certain circumstances a health or social care professional can set aside information sharing condition such as consent or respecting an objection, for example   * When a patient lacks capacity * Where they are required by law to share information, or * Where a denial or objection would put someone at risk of harm |
| **Direct care** | A clinical, social care or public health activity concerned with the prevention, investigation and treatment of illness and the alleviation of suffering of individuals. It includes supporting individuals’ ability to function and improve their participation in life and society. It includes the assurance of safe and high quality care and treatment through local audit, the management of untoward or adverse incidents, person satisfaction including measurement of outcomes undertaken by one or more registered and regulated health or social care professionals and their team with whom the individual has a legitimate relationship for their care. (Source: HSCIC Confidentiality guidance for health and social care – references) |
| **Direct care team** | For example:   * GP and GP Practice staff; * specialist doctors such as a hospital consultant and their clinical team; * nurses and midwives; * physio and other therapists; * radiology and laboratory staff processing test results; * pharmacists; * social care staff; * staff supporting teams such as administrative staff who book appointments, make sure paper records or other relevant information is available at the point of care, write letters, greet people at clinics, receive telephone calls and other supporting tasks; |
| **Fair and lawful** | First principle of the Data Protection Act says personal information should only be used in a way that is fair to the individual and compliant with all relevant laws. |
| **Fair processing**  **(see fair and lawful processing)** | Legal requirement of the Data Protection Act to tell people who you are, what you do with their personal data and other information necessary to make that use “fair”. |
| **Health or social care professional** | A regulated member of staff of a public body who exercises functions in connection with the provision of health services or of adult social care in England. |
| **Individual** | The patient, client, customer, service user or any other term used to describe the person on the receiving end of health and social care services. |
| **Necessary** | A key term used in Schedules 2 & 3 of the Data Protection Act 1998 as a condition for processing (e.g. “necessary for a medical purpose”) and should be taken to mean as being essential to achieve a specific result that would not be achieved without using personal data. |
| **NHS Constitution**  <https://www.gov.uk/government/publications/the-nhs-constitution-for-england> | The NHS Constitution establishes the principles and values of the NHS in England. It sets out rights to which patients, public and staff are entitled, and pledges which the NHS is committed to achieve, together with responsibilities, which the public, patients and staff owe to one another to ensure that the NHS operates fairly and effectively. |
| **Object** | A basis for individuals to express their preference to stop the sharing of information that they provided in circumstances where it was reasonable to assume that the information concerned was subject to the common law provisions |
| **Personal data** | Has a specific definition in the Data Protection Act (section 1) summarised as information about a living individual who can be (a) identified from those data or (b) from those data when matched to other data held or accessible to the person holding the data. |
| **Personal confidential data** | This term describes personal information about identified or identifiable individuals ‘given in confidence’ and ‘that which is owed a duty of confidence’. Used interchangeably with ‘confidential data’ “personal data” “identifiable data” in this document. |
| **Provider** | A term used to describe the organisations providing health and social care services |
| **Voluntary sector/3rd sector** | registered charities and non-charitable voluntary bodies also known as “not for profit” organisations who work for the public interest providing a range of services for the community |