

Sharing Personal Data – BHBIA Quick Guide

April 2025

This guide summarises the latest guidance and support available when sharing personal data between data controllers

When sharing data, it is important to consider the transfer process and ensure best practice is being applied.

Contractual obligations

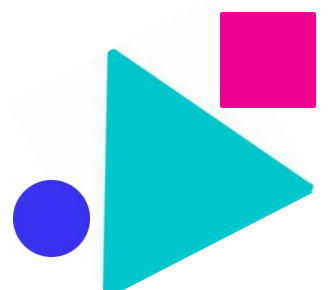
It may be that there is already a data sharing agreement in place between two parties based on the original contract and its terms and conditions. A first step when assessing the need for a data sharing agreement is to check whether this is in place already and then decide what is required above and beyond this

NHS Data Sharing Agreement Template

The NHS has made available a controller to controller 'Data Sharing Agreement (DSA) Template'. This is a high-level data sharing agreement that you can use to outline the basics of personal data sharing between organisations.

<https://digital.nhs.uk/services/data-access-request-service-dars/dars-guidance/term-of-data-sharing-agreement>

There is also guidance on what the different sections of the template are designed to do. Whilst it has not been developed with business intelligence in mind it could be useful to BHBIA members sharing personal data; at the very least it acts as a prompt to for all the issues to be considered when data sharing. Do bear in mind though that a DSA is not legally binding; if enforceable rights are required, then these need to be framed in a Data Processing Agreement, rather than a DSA.



ICO Data Sharing Code of Practice

The UK Information Commissioner's Office (ICO) launched a statutory Data Sharing Code of Practice:

"to give individuals, businesses and organisations the confidence to share data in a fair, safe and transparent way in this changing landscape. This code will guide practitioners through the practical steps they need to take to share data while protecting people's privacy."

<https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/data-sharing/data-sharing-a-code-of-practice/>

The Data Sharing Code contains practical guidance on how to share personal data fairly and lawfully, and how to meet your accountability obligations. It does not impose any new conditions on data sharing but will help you comply with your legal obligations under the UK GDPR and the DPA 2018. Data protection law is an enabler for fair and proportionate data sharing, rather than a blocker.

The code is mainly aimed at organisations that are controllers sharing personal data. Data sharing with a processor or within organisations is not covered by the code.

Data sharing includes

"the disclosure of personal data by transmission, dissemination or otherwise making it available".

This includes:

- providing personal data to a third party, by whatever means
- receiving personal data as a joint participant in a data sharing arrangement
- the two-way transmission of personal data
- and providing a third party with access to personal data on or via your IT systems.

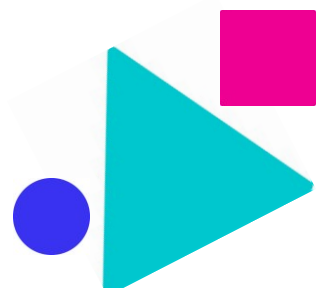
We have reproduced key parts of the ICO's Data Sharing Code below but we suggest you familiarise yourself with the full Code and use it to check the detail.

Deciding to share data

We recommend that as a first step you carry out a Data Protection Impact Assessment (DPIA), even if you are not legally obliged to carry one out. A DPIA will help you assess the risks in your planned data sharing and determine whether you need to introduce any safeguards. This will also help to provide reassurance to those whose data you plan to share. Do remember you must carry out a DPIA for data sharing that is likely to result in a high risk to individuals.

Data sharing agreements

It is good practice to have a data sharing agreement (DSA).



Data sharing agreements set out the purpose of the data sharing, cover what happens to the data at each stage, set standards and help all the parties involved in sharing to be clear about their roles and responsibilities.

There is no set format for a DSA; it can take a variety of forms, depending on the scale and complexity of the data sharing.

You should address a range of questions in a data sharing agreement:

- Who are the parties to the agreement?
- What is the purpose of the data sharing initiative?
- Are we sharing data along with another controller?
- Which other organisations will be involved in the data sharing?
- What data items are we going to share?
- What is our lawful basis for sharing?
- Is there any special category data, sensitive data or criminal offence data?
- What about access and individual rights?
- What information governance arrangements should we have?
- What further details should we include? E.g. a data sharing request form

Accountability

Accountability obligations mean that if you are involved in a data sharing arrangement, you are responsible for your compliance with the GDPR or DPA 2018, and you must be able to demonstrate that compliance.

There is a general obligation to evidence your compliance and justify your approach, so you should maintain relevant documentation and adopt additional measures as necessary.

If you have a DPO (data protection officer) they should be closely involved from the outset in any plans to enter into a data sharing arrangement.

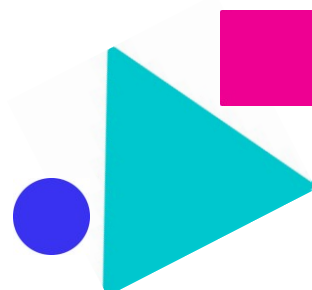
Fairness and transparency in data sharing

The gateway to getting data sharing right is always to share personal data fairly and in a transparent manner.

- You must treat individuals fairly and not use their data in ways that would have unjustified adverse effects on them.
- When you share data, you must ensure it is reasonable and proportionate
- You must ensure that individuals know what is happening to their data
- Before sharing data, you must tell individuals about what you propose to do with their personal data in a way that is accessible and easy to understand.

Lawfulness

In order to comply with the lawfulness principle, you must ensure that your data sharing is lawful in beyond just data protection law There might be other considerations such as specific legal requirements that need to be met, for example, Copyright restrictions.



Lawful basis for sharing personal data

You must identify at least one lawful basis for sharing data before you start. You must be able to show that you considered this before sharing any data, in order to satisfy the accountability principle.

Security

Data protection law requires you to process personal data securely, with appropriate organisational and technical measures in place.

The rights of individuals

In a data sharing arrangement, you must have policies and procedures that allow data subjects to exercise their individual rights easily. There are additional requirements if your data sharing involves automated decision-making.

Sharing personal data in databases and lists

The transfer of databases or lists of individuals is a form of data sharing. It is your responsibility to satisfy yourself about the integrity of the data supplied to you.

You should make appropriate enquiries and checks, including the following:

- confirm the source of the data
- identify the lawful basis on which it was obtained and that any conditions about that lawful basis were complied with
- check what individuals were told at the time of handing over their data
- verify details of how and when the data was initially collected
- check the records of consent, if you are relying on consent
- review a copy of the privacy information given at the time of collection of the data
- check what information was given to individuals
- check that the data is accurate and up to date
- ensure that the data you receive is not excessive or irrelevant for your needs.

You must tell data subjects who you are sharing their data with, and for what purposes. You must give privacy information to data subjects at the same time as collecting the data from them or within a reasonable period after obtaining the personal data.

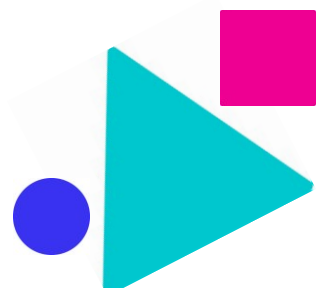
It is good practice to have a written contract with the organisation supplying you with data.

Data sharing and children

If you are considering sharing children's personal data, you must take extra care.

You may share children's personal data as long as you can demonstrate a compelling reason to do so, taking account of the best interests of the child.

You should carry out a DPIA to assess and mitigate risks to the rights and freedoms of children, which arise from your data sharing.



Data sharing in an urgent situation or in an emergency

In an emergency you should go ahead and share data as is necessary and proportionate.

An example of an emergency situation is the risk of serious harm to human life.

Annexes within the Code

A: Data sharing checklist providing a step-by-step guide to deciding whether to share personal data. It highlights what you should consider to make sure that your sharing complies with the law and meets individuals' expectations.

B: Data sharing request form template for use by the organisation making the request for data sharing.

C: Data sharing decision form template for use by the organisation taking the decision to share data.

Further information

For further detail on all guidelines please see the BHBIA Legal & Ethical Guidelines for Healthcare Market Research at <https://www.bhbia.org.uk/guidelines-and-legislation/legal-and-ethical-guidelines>.

If you have any queries about this Quick Guide or the BHBIA Legal & Ethical Guidelines for Healthcare Market Research, please visit www.bhbia.org.uk and submit your query via 'My BHBIA'. Please note: this ad hoc advisory service is available to full BHBIA members only.

Prepared by the BHBIA's Ethics & Compliance Committee April 2025

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