

It's all about me:

Information sharing, collection and storage.

Why the way in which social care collect, store and share information and data is important.

When supporting people in social care in a variety of ways and settings, we'll be given and collect large amounts of data and information. Often the information is personal and knowing it can make a tremendous difference to the quality of care we can offer.

As we encounter information and data so much as part of our work, it's easy to think of it as a by-product of the care we deliver, something that is needed but not core to what we do.

However, this would be a wrong assumption. Its appropriate use is in fact at the heart of how we promote, deliver and maintain quality care and how we plan that care in the future.

In this first of a series of guides, we set out the reasons why information collection, sharing and storage is important, how the law is changing and why those who work in social care, at all levels and in all types of role, have a duty to uphold data principles.



For a comprehensive guide on Information Sharing for Social Care Employers please visit our website.



What is 'Information and data'?

In social care, you may be asked to share both data and information so it's important to understand the difference. If information is shared well it can lead to people receiving improved services and achieve better outcomes.

- data is a term used to describe statements or numbers that are factual and not the product of interpretation.
- information is the output of a process that summarises, interprets or represents data to convey meaning.

For example, when you put together individual pieces of data collected from individuals to give an overview, that becomes information e.g. number of males using your service etc. Another example may be weight or height (data) but when analysed to provide a BMI score for example, this score then becomes information.

Why is it how we use information important?

It's about dignity and privacy...

All care services should ensure that those they support are treated with dignity and respect. People's personal information is unique to them, it can describe their history, their achievements, and their losses.

Think for a moment of yourself and one moment in your life that was important to you? Perhaps you had an illness or relationship breakdown? Who would you want to know about this information? If there are people that you wouldn't want to know, why is this? How would it make you feel if they did know?

From your reflection above, you can understand that inappropriate use of personal information can lead to a mistrust in those who have used it without permission.

Equally, think of a time when it would have been useful if someone would have known something about you before you told them? Would it have saved time, distress or perhaps been dangerous not to know (for example, having a severe allergy?).

In these circumstances, you would want those involved to share information in an appropriate way.

Therefore, treating information with the respect it deserves is an important way of a person receiving dignified and respectful care.

It's about helping people to 'tell my story once'...

Many people that use care services, also receive support from other agencies. People who use services often voice the frustration of having to tell their story numerous times to different agencies. It can be very helpful and efficient to find safe ways in which to share information between these services to avoid people to have to tell their story numerous times to each organisation.

The first organisation that has contact with a person can be useful in explaining who else they may share their information with and why. Establishing from the start an agreed way of working. It can also be vital to share information to gain a complete picture of someone's support. In this way, concerns can be shared and evidence gathered to show a complete picture, possibly avoiding missing any major concerns or issues. Sharing information within organisations is equally important to support people well.

It's about moving towards integrated services to improve outcomes for people.

From policy, the impact of the integration agenda places a clear need for services to work differently and include their approaches to information sharing in this new way of working. Planning of future services, giving excellent information, advice and guidance all depend to some degree on the pooling of data and information across areas and between partners. Working in a more integrated way means that safe information sharing in particular will be at 'the sharp end' of changing how we all work.

It's about being open and transparent...

Those using your services should be guided by you as to how you use their information and data. You should never assume their consent to you storing or sharing it. Those who use your services should give written consent to you, after you've explained:

- how you keep their information
- what you will use it for
- how long you will keep it
- who else may have access to it.

We're all protected by the law when it comes to our personal information (see "It's about abiding by the law...") and you should be ensuring you uphold this via an open and transparent conversation with those who use services. Much of the information we hold regards that person's direct care. Where sharing information about direct care is in the person's best interests, we have a duty to do so and should always work to this principle.

It's about abiding by the law...

The law is clear that data should be protected and treated with respect. The Data Protection Act (DPA) (1998) sets out this framework, though it will be superseded by the General Data Protection Regulations (GDPR) on 26 May 2018. There is a legal obligation to share information securely and appropriately; the duty to share information can be as important as the duty to protect patient confidentiality.

All staff involved in processing, storing or sharing information need to act within the law and be made aware of the guidance.

So for all these reasons, we can see why information sharing, storage, collection is important. Let's now look at what the role of information governance is and how the law is changing to further protect our information and data.

What is information governance and how does it help?

Information governance (IG) describes the process, procedures and policies that an organisation puts into place to protect and prescribe the way information can be used. Having excellent IG processes and procedures help to ensure that the way in which information 'flows' or moves within your organisation or between your organisation and another is undertaken in a safe, documented and controlled way which is within the law. All social care organisations should have an information governance and information sharing lead to help shape internal processes and ensure staff are clear on how and when to share information. Essentially, there should be two roles/functions within the organisation:

- someone who is responsible for managing information risks at a senior management level
- someone who is responsible for ensuring citizen/service user rights are respected.

Services need to have someone who is responsible for how data and information is kept, shared and used at both of these levels. Whatever the size or function of your social care organisation, it's **vital** that someone has the responsibility for IG. Without this in place, you could be exposing your organisation and the people you support to risk. From next year, the GDPR regulations will also mean that poor data governance exposes your organisation to possible fines.

([Click here](#) for more detail on this and have a look at our next guide)

Risk can also be increased by not being fully aware of how to be 'cyber secure'. Much of the data and information that we gather, store and use is of great value to criminals. You will have heard of examples of where whole systems are disabled and 'held to ransom' by cyber criminals. To lower the risk of cyber crime, all staff need to know how to protect the data and information you have. To help you, we've worked with partners to produce 'An Introduction to Cyber Security', a helpful guide for social care employers.

How are the law and regulations changing?

Since 1998, England has had data protection laws to protect how our information is used. The Data Protection Act (1998) will be familiar to most social care employers and gave a legal framework within which to act. In the intervening years, the Government has asked Dame Fiona Caldicott, the National Data Guardian, to periodically report on how data and information are being protected and used with health and care. These reports have resulted in many recommendations, Principles and Standards. These will now be taken forward as part of data protection reform.

On 26 May 2018, the General Data Protection Regulations come into force and social care employers will need to be compliant by this date. It is anticipated these will be incorporated into UK Law over the next year. The regulations will be enforceable by the Information Commissioners Office, including substantial fines for 'data breaches' from 26 May 2018. They will be introduced into all EU countries automatically on this date but will also be enforced now in the UK (despite any implications of Britain leaving the EU) from **25 May 2018**. Many of the GDPR's main concepts and principles are much the same as those in the current Data Protection Act (DPA), so if you are complying properly with the current law then most of your approach to compliance will remain valid under the GDPR and can be the starting point to build from. However, if you are not confident that you are DPA compliant, GDPR could mean a major change and re assessment of your processes,

training and documentation. For all, there are new elements and significant enhancements, so you will have to do some things for the first time and some things differently.

How do I find out more?

In the second of these bulletins, we will be looking in detail at the GDPR, what the regulations mean for you and what you may need to do to prepare you and your workforce.

In our third guide, we'll also focus on the information governance toolkit and its role in IG and how it can help with the training of staff in this area.

For more information on GDPR in general [click here](#).

Information and data sharing, storage and protection is the responsibility of everyone who works in social care. It's a vital component of how we ensure the dignity and privacy of the people we support. It is also a requirement of law that can incur fines if ignored. Information governance processes are an important part of ensuring all staff working within an organisation are complying to the law and require that a person within an organisation has a designated role and expertise in this area.

Where can I find out more?

The authoritative source of advice and guidance about the rules on using and sharing information in health and care.

<https://digital.nhs.uk/information-governance-alliance>

Further details on GDPR and what it means for you.

<https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/>

The Centre of Excellence for Information Sharing works with local places and central government departments to investigate, challenge and overcome cultural barriers to information sharing to help public sector reform.

<http://informationsharing.org.uk/>

Resources and guidance on sharing information and adult safeguarding.

<http://www.scie.org.uk/care-act-2014/safeguarding-adults/sharing-information/>

A comprehensive guide on information sharing for social care employers.

<http://www.skillsforcare.org.uk/Documents/Topics/Digital-working/Information-sharing-for-social-care-employers.pdf>

