

A black and white photograph of a classroom. In the foreground, a man with glasses is looking towards the right. Behind him, several other people are seated at desks, some looking towards the front of the room. On the desks, there are papers, a water bottle, and a white mug. A book titled 'Care date guidelines' is visible on the desk in the foreground.

Information sharing for social care employers

Updated February 2017

Introduction

Government policy has outlined the importance and increasing need for information sharing between organisations at a local level. [The Information Governance Review: To share or not to share](#)¹, led by Dame Fiona Caldicott, states that every citizen should feel confident that information about their health should be securely safeguarded and shared appropriately when in their interest. Everyone working in social care and health should see the use and safe sharing of information as part of their responsibility. This is why Skills for Care have produced this guide to help social care employers think through these issues and begin to skill their staff to meet these new challenges.

Data and information

In social care, you may be asked to share both data and information so it is important to understand the difference. The Caldicott Review states that:

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

For example, you may have data on how many people use your services. You may also have information about the people that use that service, for example their name and address.

Some organisations, e.g. local authorities with adult social care responsibilities, will have a Caldicott Guardian, that is, a senior figure responsible for leading on issues to do with information and data sharing and information governance.

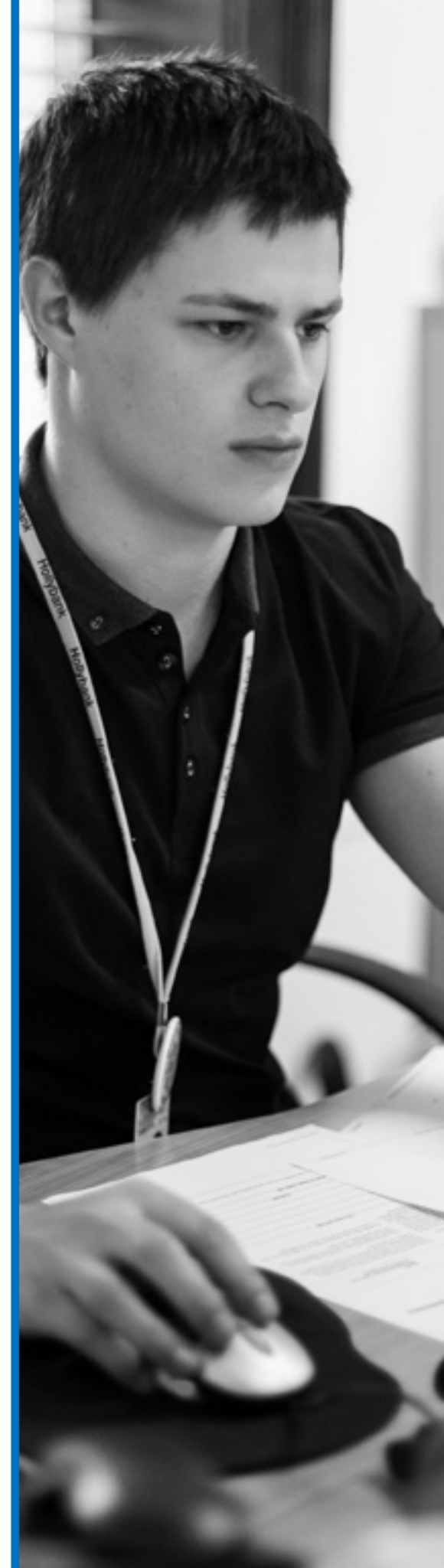
What is information governance?

Information Governance ensures necessary safeguards for, and appropriate use of, patient and personal information. Even though many organisations will not have a Caldicott Guardian, 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.

Sharing information and information governance present challenges to employers. Concerns about data protection, working with different systems, confidentiality, making sure all staff are all aware of processes are some of the things employers highlight as issues.

This guide will help you think about the big issues that are facing social care employers and give you some guidance on thinking these through for your organisation.

1. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/192572/2900774_InfoGovernance_accv2.pdf



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Why do I need to share information with other agencies?

With the publication of the Caldicott Report and the acceptance of its recommendations by government comes a understanding that social care employers and other partners have a legal duty to share information appropriately. 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. All of this also depends on the people that use your services consenting and being aware of how you may use their data or information.

The Data Protection Act (1998) and the Caldicott Principles are the essential guides to understanding your responsibilities as an employer in this area.

- You can find out more [here](#) about Data Protection Act and the Caldicott Principles.
- Guidance on specific topics, e.g. the legal duty of care can be found on [the Information Governance Alliance website](#).
- Comprehensive guidance on all aspects of information governance can be accessed through [NHS Digital's Information Governance Toolkit](#).

Aside from the legal requirements, there are other benefits to sharing information and data which include:

- Making sure the right people are involved in offering the right help to the right people.
- With an emphasis on prevention and well-being paramount in the Care Act (2014), it is vital that services come together to share information in the correct manner, spotting where people can be supported at a 'low level' by a wide range of services before needs escalate.
- Integrated care is seen as increasingly important and this cannot be delivered without effective information sharing. Many localities are developing new ways of working and the lessons learned and case studies are available from the LGA website.
- Professionals can work together more efficiently
- Giving information only once and sharing appropriately can lead to more efficient use of resources.
- To ensure proper safeguarding.
- Sometimes, failing to share information can have devastating impacts. Concerns about the safety or well being of an individual not shared with others or collectively considered with others who have contact with them has led to several high profile enquiries into deaths through neglect or abuse. [Click here](#) to explore how the failure of information sharing had a devastating impact on one individual.
- Time and time again, people who use services talk of having to 'tell their story' multiple times to many different agencies. Often the assumption from the individual is that agencies will 'talk to one another' and share data, when in fact they do not. Information sharing is key to delivering better, more efficient services that can be coordinated around individual needs.



"For years now it's been like, who do you go to first? You end up with one person doing this job and another person doing that job, then sometimes there's an overlap. The more you're bombarded with information and questions, the more confusing it gets. I hope things will become less complicated in the future so that more attention can be given to the actual service."

Karen, Wheelchair user¹.

These are all reasons why policy and law now prioritise the area of information sharing as a key way to improve services and drive up the quality of care for those who need care and support.

1. Centre of Excellence for Information Sharing, Infostory story book. http://informationsharing.co.uk/wp-content/uploads/2014/12/FINAL-BOOK_Information_Sharing_Stories.pdf

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What are Caldicott Guardians?

A Caldicott Guardian is a senior person responsible for protecting the confidentiality of individuals using care and support services enabling appropriate information sharing. A Caldicott Guardian acts as the 'conscience' of an organisation and actively supports work to enable information sharing where it is appropriate to share, and exercises judgement where the required activity is not clear cut.

For social care, organisations like local authorities with adult social care and public health responsibilities and commissioned services where the commissioner requires a Caldicott Guardian will have one in place. Each NHS organisation that has access to patient records is required to have a Caldicott Guardian, including trusts, Clinical Commissioning Groups (CCGs), CSU's, strategic health authorities, and special health authorities.

Find out who your nearest Caldicott Guardian is by clicking [here](#).

Not all social care organisations will have or be required to have a Caldicott Guardian – it wouldn't be possible or practical for smaller or medium sized employers to have such a dedicated role. However, all social care organisations are required to share information and for that reason, should have an information governance lead and clear processes and structures to enable appropriate information sharing. See the first section '[Why do I need to share information with other agencies](#)' to find out more about an organisations requirements to share information and information governance.

For small social care employers, this may mean that these functions will be taken on by a trustee or a data controller as part of their role.

“Do we need a Caldicott Guardian or an Information Governance lead?”

You can find out more about Caldicott Guardians and NHS Digital on their [website](#). This sets out what a Caldicott Guardian does and the process for becoming a Guardian. It will also help you to think about who in your organisation may need to take some of these functions as part of their existing role.

The Information Governance Alliance also has number of networks for Information Governance (IG) leads, for professionals to come together to share practice and issues. You can find out more about the network of IG leads on the [IGA website](#).



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What are the Caldicott Principles?

The [Caldicott Review](#) and [the Data Protection Act 1998](#) set out clear principles for organisations to follow when thinking about confidentiality and information sharing:

1. Justify the purpose of sharing information - the reason should be clearly defined and information used for the specific purpose
given and processed in accordance with the rights of the individual
2. Don't use individuals identifiable information unless it is absolutely necessary and make sure information shared is accurate
3. Use the minimum necessary individual-identifiable information; making sure information is relevant and not excessive.
4. Access to individual identifiable information should be on a strict need-to-know basis and should be kept secure at all times remembering issues of confidentiality.
5. Everyone with access to individual identifiable information should be aware of their responsibilities
6. Understand and comply with the law remembering that information should not be transferred to countries outside the EEA (European Economic Area) or countries without adequate protection until suitable arrangements are in place
7. The duty to share information can be as important as the duty to protect confidentiality. This shifts the balance for social care employers away from not sharing information to emphasise the responsibility to share when appropriate.

Data and information security

It is vital to have systems, processes and behaviours that ensure individuals information and data is kept safely, in accordance with The Data Protection Act and the Caldicott Principles. Social Care employers should consider how the understanding and behaviours of their staff contribute to this.

For example, are staff;

- securing USB sticks with data or information stored on them?
- keeping paper files locked away?
- using strong passwords?
- backing up data regularly?
- keeping passwords secure (not on sticky notes by their screens!)

Lasa have a guide to being safer on line. To see this, click [here](#). They also have a guide to compliance to data protection on their website. To see this click [here](#).

“What are the legal aspects of data protection that my organisation should know about?”

You will find out more about your legal duties around data protection from the [Information Commissioners Office](#). This is a very clear guide for those who have day-to-day responsibility for data protection and gives practical examples and answers the most frequently asked questions.

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How do I know what information to share?

One of the first things that employers often ask is what information should I be sharing? There is no 'one answer' to this and part of the answer will be created locally by understanding what benefits could be possible by sharing certain types of data or information. We need to remember that not all information needs to be shared and Caldicott Principles remind us that we need to be clear and justify the purpose when sharing any information and ensure we comply with the law.

Working in partnership with the other local agencies you will be sharing with will help you understand the purpose of the sharing and any specific goals you want to achieve. Understanding the specific purpose will guide you to understand what information may need to be shared.

Some questions that might be helpful for kick starting this process of understanding your purpose include:

- What is the specific purpose of the information you wish to share?
- How will collecting it contribute to better outcomes for individuals?
- How will sharing it contribute to better outcomes for individuals?
- Who else would benefit from this process as well as individuals (what other services or bodies could make efficiencies or improve responses via the use of this information?)
- Who potentially has the information you want? Who are the partners stakeholders?
- Have you begun to think about how you will gain consent from individuals to share information?
- Have you begun to think about how you will deal with objections to information sharing from individuals?

It is also important at this stage to openly identify, discuss and mitigate for the risks to all involved. These may be;

- Risks caused by inaccurate data
- Risks caused by sharing inappropriate information
- Risks caused by poor quality information
- Risks to individuals' privacy
- Risks of sharing data within or between insecure IT systems

Other employers have struggled with many of these areas and Living Well-Penwith, a pioneer project looking at integrating services, has shared their experience of working with partners to determine what information to share. Watch the video case study [here](#).



Cornwall video



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Each organisation will have different challenges when it comes to sharing information but the Centre of Excellence for Information Sharing has mapped a journey for employers to help identify and manage issues that crop up along the path of sharing information. This can be done collectively with stakeholders and partners if you want.

■ What are we trying to achieve?

- Different organisations will want to achieve different things. Are you aiming for a 'tell me once' approach for people who use services? Perhaps you want to set out a clear plan for several organisations? Whatever you need, it is important to be clear from the outset what your vision is for the work.

■ What information governance mechanisms should we establish?

- What do you already have in place, are they helpful or need review? Who is currently responsible, what processes do we have, what capacity is available to change? How can we share learning? How do we remain transparent? Do we need to complete the [NHS Digital hosted Department of Health Information Governance Toolkit](#)?

■ How can we determine what information sharing requirements we have?

- What are the overall goals and purpose? What are the needs of different stakeholders and how can these be met? How can we share information practically?

■ How do we identify and assess the risks and benefits of sharing information?

- What are the risks? How do we deal with non-disclosure, poor quality and security issues? How do we assess the risk for privacy?
- How can we be clear of the benefits to sharing? What benefits have others had and how can we share this with senior managers?

■ What is the legal basis for sharing?

- What is the basis for sharing? Are we clear on what needs to be shared and with whom? Have data protection issues been considered and how do we establish consent and objection processes?

■ How will we monitor our information sharing?

- What steps should we put in place to make sure we know how often information is shared? How can we monitor processes to make sure they are working? how will we know if staff are using policies and processes correctly? How do we keep data safe?

For some smaller organisations, there can be challenges of how they use the data they have across their own organisation in a way which helps people get better outcomes but also complies with data protection. [Click here](#) to hear a social enterprise in Cumbria talk about their reasons for moving their systems to a cloud based system and what benefits this has had for them.



Cumbria film

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Effective partnership working requires a consistent approach from all partners to informing and gaining consent from individuals to share their data. It will be useful here to reconsider why you and your partners wish to share the information. It is also important to consider how employers and their partners work with the public to co-create services and create understanding for how their data is used. The Centre of Excellence for Information Sharing has developed a [useful tool with a range of case studies](#), detailing how others have engaged the people that use their services and the wider public.

The [Data Sharing Code of Practice](#) provides a guide on issues to consider when recording your information sharing decisions and this will perhaps affect your own existing governance procedures and organisational policies.

The development of a shared protocol is key to the effectiveness of the process. From this will come shared procedures, policies and greater clarity about roles and responsibilities within each partner organisation. It may be possible to create a shared digital record, where all partners involved in a person's care will input and share information onto one system. The Centre of Excellence in Information Sharing have examples of how people have developed a digital care record in partnership; for example, [Airedale, Bradford and Craven who have developed a golden line approach for end of life, using an Integrated Digital Care Record](#).

At this stage, you may want to ask yourself the following questions;

- Are the existing relationships between partners honest and trusting enough to make this work?
- How will we keep data safe and secure when sharing?
- What implications might there be for the IT systems being used?
- What information may be commercially sensitive and cannot be shared?
- Are our policies, protocols and info sharing records clear enough about what the data is being used for (audit purposes individual purposes/research/planning) and why?
- What new resources might be needed to be transferred or invested into any new systems/ways of working that have been agreed?
- Are we clear enough about who is responsible for what and when?

Examples of this sort of approach of developing shared protocols include the [Derbyshire Partnership](#), [Bracknell Forest](#) and [Camden](#).

Leicester City Council developed a [Multi Agency Sharing Hub](#) (MASH) for co-located teams which can pull together relevant information on individual families.

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Case study

The End of Life Partnership in collaboration with NHS organisations and Hospices across Cheshire have introduced a Unified 'Do Not Attempt Cardio Pulmonary Resuscitation' (UDNACPR) for people nearing the end of life. Previous experience indicated that having the 'wrong' DNACPR form for different organisations led to inappropriate decision-making. For example, resuscitation following an emergency call to ambulance services. This was leading to individuals having difficult conversations about resuscitation repeatedly with different professionals.

The initiative, led by North West Ambulance Service, allows professionals to use one form only to record decisions about resuscitation. This means individuals only need have this conversation once. Professionals feel more secure as the 'lilac' UDNACPR form is now a regional policy, accepted across all providers in the South, Vale Royal & East Cheshire Clinical Commissioning Groups.

The form is printed onto lilac paper to make the patient held copy distinctive and recognisable across the services. With the patient's permission this decision is then electronically shared with other services so that if an ambulance or out of hours GP visits that they will know about the decision and may request to see the 'lilac form' if this is relevant to the situation.

An information portal has been developed to support health, social, independent and voluntary care workers in their understanding of the DNACPR alongside other end of life care related issues. [Click here](#) to view the Cheshire EPAIGE.

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Working more closely with partners and developing information sharing protocols might be something you are doing anyway and this work will slot into broader work that you are undertaking. Perhaps you are involved in integration at a local level or planning for changes in services following the Care Act implementation. If you are starting to come to terms with more integrated working, you might want to have a look at Skills for Care “[Principles of Workforce Integration](#)”

The major challenge of any [implementation](#) of change is securing a new way of working from the workers ‘on the ground’.

You may want to ask yourself the following questions;

- Are existing recording practices and procedures good enough to enable the information to be shared?
- Who needs to know about changed procedures?
- Who is the priority group?
- Do they already have a good knowledge of [data protection](#) or do we need to go ‘back to basics?’
- Have the policies been tried and tested with practitioners and do they make sense ‘on the ground’?
- What plans do we have to equip staff to talk confidently to individuals to gain their consent and understanding?
- Is it clear where responsibility for compliance and decision making lies within ‘front line’ teams?
- Are staff clear on [confidentiality](#) issues?
- Is it clear how staff can obtain advice and guidance if they are not clear?
- Is it clear how our policies relate to safeguarding responsibilities?
- Is there an [easy visual](#) or [booklet](#) to remind staff of the steps involved?
- Are we sufficiently skilled and equipped in basic computer / information security?
- What steps should we take to make sure our data is safe?

You will also want to monitor and evaluate the impact of the sharing of information. You may wish to monitor this formally via an audit or develop ‘case studies’ that show clearly how the exchange of information improved the outcome for an individual.

You can click [here](#) to see the Information Governance Alliance and the Centre of Excellence for Information Sharing discussing the types of issues that this guide has explored and what they can do to help.



**Information Governance Alliance
/ Centre of Excellence for
Information Sharing**



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There are other organisations who can help you think through information sharing in social care.

Organisation



Information Governance Alliance



Centre of Excellence for Information Sharing



LASA



Information Commissioners Office

Website

[View site >>>](#)

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