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Information sharing guidance for professionals working with children and adults at risk of abuse or neglect.

1. The purpose of this guidance.

This guidance aims to support good practice in information sharing by offering clarity on when and how information can be shared, legally and professionally, to achieve improved outcomes. The seven golden rules for information sharing and Caldicott Principles are shown in the Appendices to this document.

2. Definitions

In this document, the term '*child*' or '*children*' refers to any child or young person under the age of 18 years. The term 'adult' refers to adults who are in need of care or support and who are unable to protect themselves from abuse or neglect.

3. Why is it important to share information?

Sharing information is an intrinsic part of practice in working with children, young people or adults at risk of abuse or neglect. Sharing information can make the difference in ensuring that an individual gets the right help at the right time and prevent the escalation of needs into abuse or neglect. The risk of sharing information is often misunderstood. All those working with children and adults must understand the risks of not sharing information. However, the most important consideration is whether sharing information is likely to support the safeguarding and protection of a child or adult at risk of abuse or neglect.

Poor information sharing or a refusal to share information due to a misunderstanding about safeguarding duties has been a feature in cases where risks have been missed, dating back to the 1970s when the review into the death of Maria Colwell occurred. Poor information sharing also featured in high profile reviews such as Victoria Climbie in 2000 and Baby P in 2007. Lessons about information sharing have also featured in Serious Case Management Reviews locally and in Domestic Homicide Reviews, Serious Case Reviews and Safeguarding Adult Reviews in the UK.

For example: In the Fiona Pilkington case in 2007, there were 27 calls made to the police by Fiona, her mother and other residents who lived nearby. These calls described various anti-social behaviour acts such as:

- setting fire to the house gates and throwing stones
- bullying and making threats to kill
- attacks and threats

Fiona Pilkington killed herself and her severely disabled daughter in 2007. Following the deaths, it was found that each incident of anti-social behaviour was dealt with as a single incident and information about the family was known, but this was never shared in a way to trigger a multi-agency response.

Fears about sharing information cannot be allowed to stand in the way of the need to safeguard and promote the welfare of children and adults where it is believed that they are at risk of or suffering harm or neglect.

An individual employee cannot give a personal assurance or promise confidentiality where there may be safeguarding concerns.

4. Multi-agency Information Sharing Guidance

Key Principles of Information Sharing:

- identify how much information to share
- distinguish fact from opinion
- ensure that you are giving the right information to the right person
- ensure you are sharing the information securely
- inform the person that the information has been shared, if they were not aware of this, and that it would not create or increase risk of harm.

Record the information sharing decision and your reasons, in line with your agency's or local procedures.

If there are concerns that a child may be at risk of significant harm; or an adult may be at risk of significant harm, then follow the relevant procedures without delay.

Seek advice if you are not sure what to do at any stage and ensure that the outcome of the discussion is recorded.

5. The Legislative Frameworks for Information Sharing.

Practitioners must have due regard to the relevant data protection principles which allow them to share personal information, as provided for in the Data Protection Act 2018 and the General Data Protection Regulation (GDPR). To share information effectively:

- all practitioners should be confident of the processing conditions, which allow them to store, and share, the information that they need to carry out their safeguarding role. Information that is relevant to safeguarding will often be data that is considered 'special category personal data' meaning it is sensitive and personal
- where practitioners need to share special category personal data, they should be aware that the Data Protection Act 2018 includes 'safeguarding of children and individuals at risk' as a condition that allows practitioners to share information without consent
- information can be shared legally without consent, if a practitioner is unable to, cannot be reasonably expected to gain consent from the individual, or if to gain consent could place a child at risk.

- relevant personal information can be shared lawfully if it is to keep a child or individual at risk safe from neglect or physical, emotional or mental harm, or if it is protecting their physical, mental, or emotional well-being.

At the time this information sharing guidance was being written the Justice Reform Act 2021 received Royal Assent. This legislation provides for regulations to be made regarding information sharing with the Department of Home Affairs where disclosure is necessary or expedient:

1. for the purpose of public safety;
2. for the purpose of preventing or reducing crime, disorder or anti-social behaviour;
3. for the purpose of safeguarding the welfare of a particular person; or
4. otherwise in the public interest

6. Identifying and recognising abuse or neglect in children and adult's lives.

All professionals have a duty to be alert to recognising abuse and neglect and aware of the complexities in identifying triggers and signs of abuse. Being aware of the manifestations of abuse and neglect in children and adults and feeling confident in responding to this, can help professionals navigate the complex issue of consent. Where there are clear safeguarding issues the issue of consent is less complex.

For example: Sinita, aged 7, goes into school on a Monday morning with a bruise to the side of her face and some areas of broken skin on her cheek. She then tells her teacher that her stepfather punched her in the face for refusing to brush her teeth on Sunday morning. This is a clear disclosure of physical abuse and it is clear that parental consent to share this information is not required.

For example: James is 21 years old and has a moderate learning disability and tells his support worker that his brother has introduced him to a new group of friends. These friends have asked James to take a package to another group of friends, after doing this they paid him £100. The package contained drugs. He tells his support worker that he is due to deliver another package this weekend and is looking forward to putting all of his savings towards an Xbox. James had made a clear disclosure of being criminally exploited. As this is a clear safeguarding issue there is no need to seek his consent (if he has capacity about this issue) or the consent of his parents, before sharing this information.

For example: Ada is open to the drug and alcohol team as she has had long-standing substance misuse issues. Ada has two children, one aged 5 and one aged 18 months. The children's father does not live with them. Ada tells her key worker that she used a massive 'binge' of heroin last night and her friend found her 5-year-old playing with the used syringe, only just stopping her from breaking the skin. Ada found this funny. The worker is aware that the children have been on child protection plans in the past due to neglect. Ada has described a very high risk situation for the 5-year-old and that both children were not adequately cared for whilst Ada took drugs. Ada also shows a lack of awareness of the level of risk this placed the children at. This is a clear safeguarding issue about which no consent

is required, although it would be good practice to inform Ada that a referral was going to be made.

For example: Sally has a young baby called Maria. Sally tells her health visitor that she has witnessed Maria having 'seizures'. When the health visitor speaks to the baby's father and grandparents, they are concerned but have never actually witnessed any seizures. Recently Maria has been prescribed carbamazepine to reduce the frequency and severity of the seizures, this medication does not appear to have any effect.
Sally reports to her health visitor that last night Maria had such a severe seizure that she went blue around her lips. The health visitor is very concerned that the prescribed medication does not appear to be alleviating Maria's seizures, her health needs appear to be becoming higher and higher risk and it is only Sally that has actually witnessed a seizure in the preceding 9 months. The health visitor becomes concerned that Maria doesn't actually suffer from seizures and that Sally is making false reports about this. The health visitor makes a referral to children's services without the mother's consent. This is in line with published guidance on Fabricated and Induced Illness or Perplexing Presentations[1] where research has shown that by informing the abusing parent this increases the risk to children.

7. What is Consent?

In most cases where there are no child or adult protection concerns, you must seek consent. Where a child does not have the competence to understand and make their own decisions then consent must be sought from a person with parental responsibility for that child.

Equally where an adult at risk of abuse or neglect has the capacity to give their consent this should be sought before sharing information. Where a young person aged 16 years or above does not have the mental capacity to give consent a making safeguarding personal visit needs be undertaken and consideration of whether their consent can be overridden.

Consent is defined as:

> *"any freely given, specific, informed and unambiguous indication of his or her wishes by which the data subject, either by a statement or by a clear affirmative action, signifies agreement to personal data relating to them being processed"*

Consent may be given verbally or in writing but where possible it is always better to get that consent in writing. If consent is given verbally you must make a record that clearly evidences how that consent was signified. This is to avoid any future dispute.

In most cases, you are required to obtain explicit consent. This means there is no doubt as to the wishes and agreement of the person.

Consent must be freely given. A person cannot be coerced, for example, you cannot imply that if consent is not provided then your concern will be turned into a child protection matter and the information shared anyway. Equally, informing someone that are going to make a referral and share information is not the same as gaining consent.

[1] Perplexing Presentations (PP)/Fabricated or Induced Illness (FII) in children – guidance – RCPCH Child Protection Portal

Consent must be specific and informed. You must be open and honest and cannot mislead or deceive. Ensure the person understands what information you intend to share, why you believe it is necessary to do so, who you intend to share the information with and what you expect will happen as a result.

A person may wish to limit the consent they are prepared to provide. For example, a person may consent to the disclosure of the information to one particular party but not to others. You should respect any limitations and ensure that those receiving the information also know and respect those limitations.

Remember that consent may be withdrawn at any time and you must respect that decision.

However, where consent is restricted or withdrawn the risk to children and or adults needs to be carefully re-evaluated at this stage to consider whether the withdrawal of consent could lead to an individual being at risk of significant harm.

For example: Gary is a single parent of three children. He and his wife have separated and both parents had significant alcohol misuse issues in the past. When Gary and his wife were together their alcohol use increased until children's services became involved. After assessments and support from the substance misuse team Gary decided to separate from his wife and put himself forward to care for his children as a single carer. The assessments of Gary were positive and he moved to Douglas with his three children.
Gary has consented for the school to share information with the school nurse and local CAMHS team. He has not consented to information being shared with children's services as he found their interventions in the past to be stressful. This limited consent was clearly recorded on each of the children's records.
Gary's wishes were respected until it was observed that he smelt of alcohol when dropping the children off to school and their attendance had dropped suddenly. The safeguarding lead had increasing concerns that Gary was starting to drink alcohol again after having abstained for three years. As a result the safeguarding lead shares the concerns with Gary and informs him that his wish to limit consent to the sharing of information with children's services needs to be overridden due to concerns about the safety of the children.

Where a professional has concerns about abuse or neglect - consent is not required. Information should always be shared to safeguard a child or an adult. Only in very rare circumstances should information not be shared - for example in cases of Fabricated and Induced Illness or Perplexing Presentations – such as Maria.

8. What if an adult at risk of abuse or neglect does not have the capacity to give informed consent to the sharing of information?

It is important to recognise the need to empower people, to balance choice and control for individuals against preventing harm and reducing risk, and to respond proportionately to safeguarding concerns. However, not all adults will always have the capacity to give their consent to information being shared. This may be due to having a severe learning disability or fluctuating capacity due to a mental illness or substance misuse.

Organisations will need to share information with the right people at the right time to:

- prevent death or serious harm
- coordinate effective and efficient responses
- enable early interventions to prevent the escalation of risk
- prevent abuse and harm that may increase the need for care and support
- maintain and improve good practice in safeguarding adults
- reveal patterns of abuse that were previously undetected and that could identify others at risk of abuse
- identify low-level concerns that may reveal people at risk of abuse
- help people to access the right kind of support to reduce risk and promote wellbeing
- help identify people who may pose a risk to others and, where possible, work to reduce offending behaviour

(SCIE 2019)

Where there are concerns about an adult's safety, there are concerns about wider safeguarding issues and they do not have capacity, the safeguarding duty overrides that of the need to protect that individual's right to privacy or for their personal information to be kept safe. If an adult is at risk of or suffering harm, it is very rare that the consent issue in this instance would block the sharing of information.

For example: if an adult was becoming increasingly at risk of harm due to hoarding and self-neglect, there should be no barriers in information sharing between agencies such as housing, the GP, benefits agency, mental health practitioners, fire brigade or police.

For example: In a recent Serious Case Management Review an adult died of natural causes following a long history of poor health. At the time of his death, he was living in privately rented accommodation, after having been evicted earlier from a local authority flat. When he was evicted, his flat was in a poor state. In this case, the local authority believed that they were not able to share information with other agencies as they did not have his consent. The coordination of services would have been greatly improved if information had effectively been shared between the emergency department, social care and mental health services, housing and the police. Following this review, the Information Commissioner agreed that contact can be made with social services and information shared due to potential safeguarding issues in eviction cases where this involves adults.

For example: Mr A is 64 years old. He has no contact with his family. He has a medical history of Korskoff Syndrome, arteriovenous malformation, epilepsy, type 2 diabetes, bilateral leg cellulitis and ulceration. Mr A has become more and more resistant to care and treatment. He is refusing treatment on his legs and is refusing to take his prescribed insulin. He told his key worker that "I'm drinking, I'm not washing, I wouldn't say I've lost the will to live but I just don't care". His key worker becomes so concerned that he discusses Mr A in supervision. The key worker feels torn, Mr A is making a lifestyle choice to drink alcohol but his use of alcohol and refusal of treatment and care is placing him at risk. Following an assessment of Mr A's capacity, it is deemed that he does not have capacity to give consent to share information with other agencies. The manager and

worker determine that he is at risk of significant self-neglect , and therefore a referral to the Adult Safeguarding team is now required. p

Where an adult presents a risk to a child and their vulnerability impacts on their ability to keep a child safe this can be challenging for practitioners who are working with adults. This can result in conflicting feelings of loyalty and sometimes a reluctance to share information without consent. In most instances, it is good practice to get the consent of any parent where you plan to share information with children's services. However, the issue of consent should not obscure safeguarding duties or prevent the sharing of information.

For example: Agata is 13 years old, she often goes missing from home, sometimes for longer than 48 hours. As a result of her going missing so often, her mother doesn't always report this to the police. Agata also frequently goes missing from school. She has told her school friend that she has an 'older boyfriend' aged 23 years old. She has also shown her friend new designer trainers and a new mobile phone that her 'boyfriend' has brought her because he 'loves her'. Agata's friend is worried as Agata is going to a party at the weekend and is going to be introduced to some of his friends. Suzi has said that she is going to try cannabis and alcohol for the first time at this party and also plans to have sex. Agata is taking her 13-year-old friends, Stacey and Paula. The information that Agata has shared with her friend is evidence of sexual exploitation. Neither Agata's nor her mother's consent would be required for the sharing of information held by the police, the school, the GP and any other services. Consent would also not be required to share information about Stacey or Paula, in evaluating the risk to them, although it would be good practice to try and gain consent where possible.

For example: in Serious Case Review x the mother had fluctuating mental health needs which sometimes meant she neglected her children and couldn't meet their needs. The mental health practitioners did not share her diagnosis or advice on how to understand when she may be experiencing periods of particularly poor mental health. This resulted in poor coordination of the support package for the mother, missed opportunities to identify when the mother's mental health was deteriorating and therefore the impact on the safety of her children. Therefore, the impact on the safeguarding of her children was not adequately considered and understood.

9. Distinguishing when to share information or not.

Where there is evidence of safeguarding issues our duties to share information are clear. Decision making becomes less clear where safeguarding issues are not so obvious. Where situations are not clear, advice should be sought from your line manager or information sharing lead.

9.1 What if consent is refused?

It is important to respect the wishes of a child or adult who does not consent to your proposed information sharing. Where a child, parent or adult does not consent to the sharing of their information this should not automatically be interpreted as an additional cause for concern.

You should, however, re-evaluate your concerns again and the information you intended to share, with whom and why. Consider whether:-

- Your concerns have been allayed by the discussion you have had with the child, parent or adult.

- Would consent be provided if you changed or reduced the information you intended to share or with whom you intended to share that information? For example, the person may be prepared to provide consent to share information with a health visitor but not children and family social services.

- Should you escalate your concern within your organisation? For example, discuss with your supervisor, safeguarding lead or information sharing lead?

For further guidance about when and how to share information, there is a flowchart below[2].

[2] Flow chart provided by the Information Commissioner

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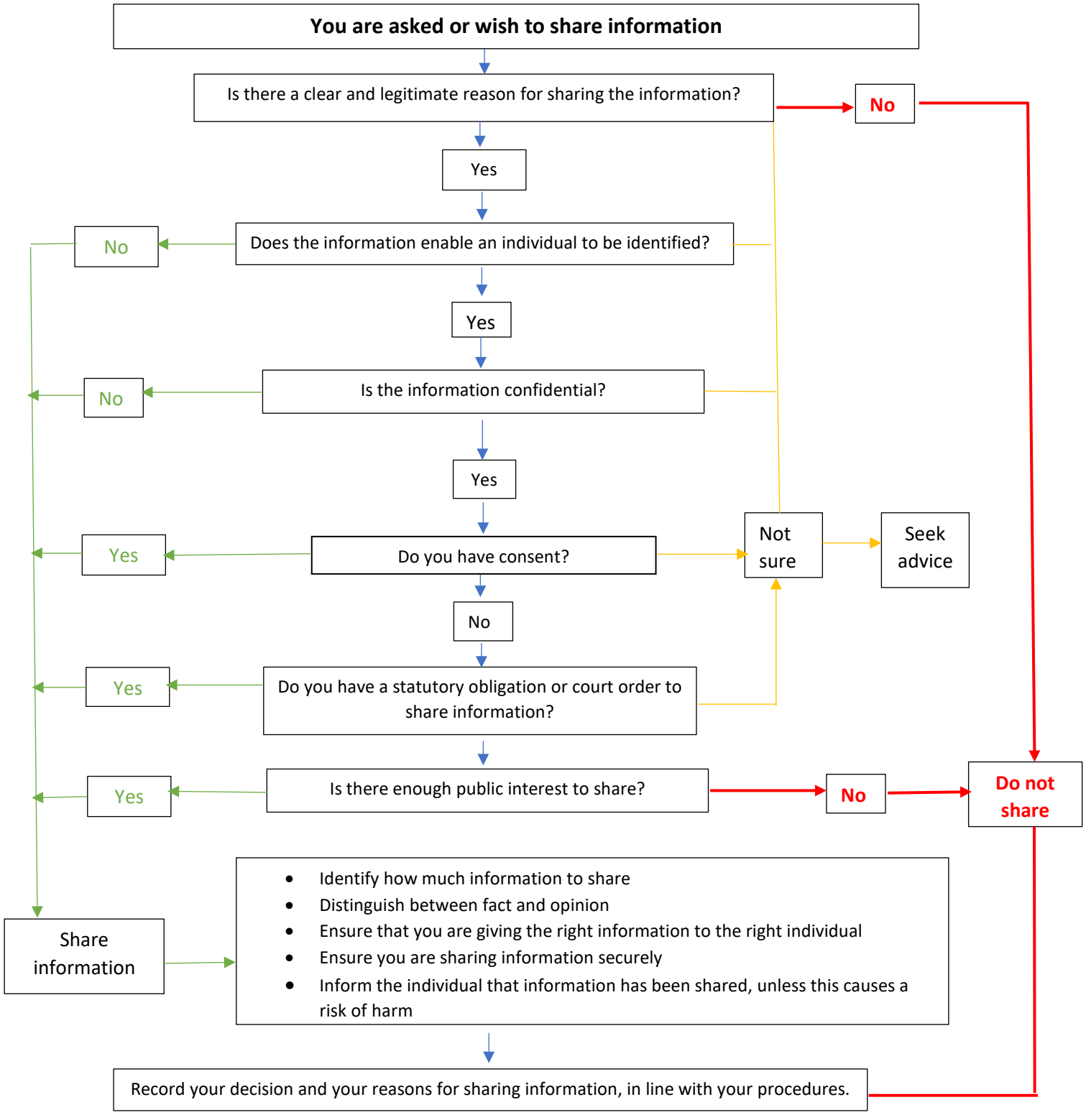

If in doubt seek advice from your managers, supervisor, safeguarding lead or Caldicott Guardian if you are not sure and record advise given.

10. What information should you share?

A concern does not justify sharing all information in your possession. You will need to identify the information that you consider is necessary, reasonable and proportionate to share in the circumstances. It is your responsibility to ensure that the information you intend to share:-

- is relevant and not excessive;
- is clear and precise and cannot be misinterpreted; (remember that different agencies use different terminology or may have a different understanding of particular terms).
- is accurate, unbiased and up-to-date;

  and

- clearly distinguishes between information that is factual, opinion, obtained from third parties or hearsay.

Decisions about what information is shared and with whom must be taken on a case-by-case basis within relevant policies and GDPR and the Caldicott Principles. The Caldicott Principles are shown in Appendix 2.

Everyone has a responsibility to keep clear and accurate records of the information received and for this information to be reported and shared in a timely manner whilst addressing any issues of confidentiality.

Where there is disagreement about information sharing, for example one agency refusing to disclose information, the Board's Escalation Policy should be used.

There is further guidance available on the Board's webpage. Including:

- A myth-busting guide: including guidance on what to do if you feel stuck
- The Board's Information Sharing Protocol, signed by the agencies

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Appendix 1 – The Seven Golden Rules for Information Sharing

1	GDPR and the Data Protection Act 2018 and human rights legislation are **not barriers** to justified information sharing but provide a framework to ensure that personal information about individuals is shared appropriately.
2	Be **open and honest** with the adult (and / or their family where appropriate) from the outset about why, what, how and with whom, information will or could be shared, and seek their agreement, unless it is unsafe or inappropriate to do so.
3	**Seek advice** from other practitioners, safeguarding leads or information governance leads if you are in any doubt about sharing the information concerned, without disclosing the identity of the individual where possible.
4	Share information with **informed consent**, where appropriate, and where possible, but respect the wishes of those who do not consent to share confidential information. **There is a lawful basis to share information without consent** if, in your judgement, there is good reason to do so, such as where **safety may be at risk**. Base your judgement on facts.
5	Consider safety and well-being. **Base your information sharing decisions on considerations of the safety and well-being** of the adult and others who may be affected by their actions.
6	**Necessary, proportionate, relevant, adequate, accurate, timely and secure**: Ensure the information you share is necessary for the purpose for which you are sharing it, shared only with those individuals who need to have it, is accurate and up-to-date, shared in a timely fashion, and shared separately.
7	**Keep a record of your decision** and the reasons for it - whether it is to share information or not. If you decide to share, then record what you have shared, with whom and for what purpose.

Appendix 2 – The Caldicott Principles

Due to rising concerns about the use or misuse of patient's confidential data, England's Chief Medical Officer created the Caldicott Principles in 1977. Dame Fiona Caldicott was the head of this review board. The name of the full report is 'The Caldicott Committee's Report on the Review of Patient-Identifiable Information'.

The Caldicott Principles are fundamentals that every institute should follow to protect any information that could identify a patient, such as their name and their records. These principles also make sure that the using and sharing of the confidential information at the appropriate time.

Organizations should use these principles as a test to determine when they should share the information or not, that could identify an individual.

There were originally 6 principles, Dame Fiona Caldicott introduced the seventh principle in April 2013 following her second review of information governance. In 2020, the National Data Guardian (NDG) again reviewed these principles and introduced the eighth principle.

- **Justify the purpose(s) for using confidential information.**
- **Don't use personal confidential data unless absolutely necessary.**
- **Use the minimum necessary personal confidential data.**
- **Access to personal confidential data should be on a strictly need-to-know basis.**
- **Everyone with access to personal confidential data should be aware of their responsibilities.**
- **Comply with the law.**
- **The duty to share information can be as important as the duty to protect patient confidentiality.**
- **Inform patients and service users about how their confidential information is used.**