



## **East Lothian and Midlothian Public Protection Committee**

### **A practitioner's guide to information sharing to support the wellbeing of adults**

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# 1) Definitions

## **Adult at Risk of Harm**

The Adult Support and Protection Act (Scotland) Act 2007 defines an Adult at risk as;

Sect 3 “Adults at risk” are adults who-

- Unable to protect their own well-being, property, rights or other interests,
- Are at risk of harm, and
- Because they are affected by disability, mental disorder, illness or physical or mental infirmity, are more vulnerable to being harmed than adults who are not so affected.

An adult is at risk of harm if:

- Another person’s conduct is causing (or is likely to cause) the adult to be harmed, or
- The adult is engaging (or is likely to engage) in conduct which causes (or is likely to cause) self harm.

## **Data Protection Act**

### **Personal Data**

Personal data is defined as “any information relating to an identified or identifiable natural person” (Art. 2 (a) and acknowledges that this includes both direct and indirect identification [e.g. you know me by name – direct identification; or describe me as the “Fieldfisher privacy lawyer working in Silicon Valley” indirect identification]).

### **Sensitive personal data**

This is personal data that is afforded extra protection under the Directive, and is defined as data relating to racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership, and health or sex life. Data relating to criminal offences is also afforded special protection.

## 2) Introduction

The development and introduction of this document was one of the recommended actions following an Initial Case Review. This document should be read in conjunction with the “*Pan-Lothian and Borders Partnership General Protocol for Sharing Information*”, which forms the over-arching document for any additional individual data sharing or data processing agreements.

This information sharing guidance is for anyone working directly or indirectly with adults (aged 16 years and above) within the public, private and third / voluntary sectors across East Lothian and Midlothian. This guidance should complement, not replace, any existing single service and / or agency information sharing, confidentiality and consent guidance.

This guidance is focused on promoting, supporting and safeguarding the wellbeing of adults.

## 3) Practitioners Summary – Key Practice Points

### Information Sharing

The principle of a duty of care is embedded in Scots Law (Common Law) this does not stem from statute but it is laid down in judicial decisions. This means that it is essentially based upon the decisions of the courts rather than reference to specific statute as determined by parliament. ***“It is generally held that, under Common Law, it is reasonable to take necessary action to safeguard a person to prevent him / her coming to harm”***. This includes the sharing and reporting of proportionate and necessary information of an adult who is known or believed to be an adult at risk of harm with or without the consent of the adult.

Good practice is to discuss your concern with the adult and / or their legal proxy such as power of attorney / welfare guardian / financial guardian/named person (Mental Health Care & Treatment Act 2003) and tell them why information is being shared, unless it is detrimental to the adult’s wellbeing or interferes with criminal investigation or other judicial process.

- Adopt a common sense approach.
- Use your professional judgement, knowledge and skills.
- Seek help and support in doing so – Line Manager / Supervisor or if your concern is one of safety follow the “*EMPPC – Adult Support and Protection Policy and Procedure 2016*”.
- Share what you consider to be necessary, appropriate and proportionate – on a need to know basis only.

- Always share your concern with the adult and/or their proxy.
- Consider the alternatives and / or implications of not sharing information.
- Always record your decision and the reasons for it.
- Follow your agency's policies and procedures and your professional guidelines.

### **Confidentiality**

- Confidentiality is not an absolute right – never promise that.
- Confidentiality does not prevent you from sharing a concern about an adult – it actually empowers you to do so.
- Be aware of the constraints and limitations of confidentiality.

### **Consent with regards to information sharing**

- Do not seek consent in situations where you are likely to share information in any case.
- Consent should only be sought when the individual has a real choice over whether the information should be shared.
- Consent should be informed and explicit – the adult must also be informed that consent can be revoked at any time.
- Consent when provided must always be recorded.
- Doing nothing is **not** an option – do not delay unnecessarily, act quickly.
- Ask yourself the five key questions – if the answer is no or you do not know then gather information to find out:
  - What is getting in the way of this adults well-being?
  - Do I have all the information I need to support the adult?
  - What can I do now to support this adult?
  - What can my agency do to support this adult? and;
  - What additional help / support, if any, may be needed from others?

### **Legislation**

Legislation does not prevent you from sharing information – it empowers you (see appendices [2](#) and [3](#)).

## 4) Principles Governing Sharing of Information

To share information, improve services and protect and support the population of East Lothian and Midlothian, the partnerships will adhere to the following principles:

- 1) Information must be of good quality and data held within each system must be accurate and up to date.
- 2) Access to personal information must be controlled on a strict need to know basis whether internally or between organisations. Sufficient reason for access must be given so as to establish a legal audit trail.
- 3) Information is provided in confidence when it appears reasonable to assume that the provider of the information believed that this would be the case.
- 4) Organisations must ensure that they share information in accordance with the law.
- 5) When consent to disclose information is sought, an individual must be made fully aware of the information required and of the purposes for which it will be used.
- 6) Personal information may be disclosed only where the agreed purpose for sharing clearly requires this or where it is lawful to do so.
- 7) Where professionals request that information supplied by them be kept confidential from an individual or organisation, the outcome of this request and the reasons for the decision must be recorded.
- 8) When disclosing information about an individual, professionals must state clearly whether the information being supplied is fact, opinion, or a combination of the two.
- 9) Agency procedures must be put in place to ensure that decisions to disclose personal information without consent have been fully considered in relation to the applicable legislation, and that these decisions can be justified and audited.
- 10) The welfare of an adult must be the paramount consideration when deciding to share information.
- 11) Careful consideration must be given to the disclosure of information concerning a dead person, and if necessary legal advice sought.
- 12) Individuals in contact with organisations or agencies must, subject to any lawful exemptions, be fully informed of the data recorded about them.

- 13) Organisations must put in place an efficient and effective complaints procedure.
- 14) Organisations must ensure that all relevant staff are aware of and comply with their responsibilities in regard to the confidentiality of personal information, and in regard to the commitment of the organisation to share information.
- 15) Staff must be made aware that unjustified disclosure of personal information may be subject to disciplinary action.

## 5) Legislative and Policy Context

It is important that you:

- Understand the legislative, policy and practice context parameters when sharing personal and / or sensitive personal information.
- Understand the limitations and constraints of confidentiality and consent, and
- Understand that you are empowered to share personal and / or sensitive personal information, if you are worried and / or concerned about an adult's wellbeing nothing prevents you from doing so as long as you record the reasons for your decision to share.

*This guidance has been informed by and is underpinned by a legislative and policy framework, further described at [appendix 2](#).*

### **Caldicott Principles**

The original Caldicott Report, published in 1997, established six principles for NHS bodies (and parties contracting with such bodies) to adhere to in order to protect patient information and confidentiality. A seventh Caldicott Principle was added in March 2013 Information Governance Review conducted by Dame Fiona Caldicott. This guidance reflects those principles ([appendix 3](#)).

## 6) Young People aged 16-18 years

It is recognised that within East Lothian and Midlothian there is a small number of vulnerable young people at risk of causing significant harm to themselves and others. This risk may be as a consequence of their own behaviour or a consequence of others behaviour towards them. To ensure that vulnerable young people aged 16-18 who may be at risk of harm have their situation assessed and respond to, please refer to the *EMPPC – Inter-agency Vulnerable Young Persons Protocol*. This protocol is intended to give guidance and a

structured framework around multi-agency information sharing, assessment, planning and decision making.

## 7) Information Sharing

### What should I consider first?

*“While it is acknowledged that practitioners need to be sure that their actions comply with all legal and professional obligations, fear that sharing genuine concerns about an adult will breach the Act (Data Protection Act 1998) is misplaced. Rather, the Act promotes lawful and proportionate information sharing, whilst also protecting the right of the individual to have their personal information fairly processed” – Information Commissioners Office 28<sup>th</sup> March 2013.*

First and foremost, you should ask yourself the following five key questions:

- 1) What is getting in the way of this adults wellbeing?
- 2) Do I have all the information I need to support this adult?
- 3) What can I do now to assist this adult?
- 4) What can my agency do to this adult? And
- 5) What additional support, if any, may be needed from others?

To answer all of these questions comprehensively, there may be a need to collate information and / or share information with the adult(s) legal proxy and other appropriate practitioners. This is particularly important where the answer to any of these questions is no or you do not know or you are unsure of the answer to any one of the above questions.

### What should I do now?

***Doing nothing is not an option! Do not delay unnecessarily!***

If you are concerned about an adult’s wellbeing then you should start by asking yourself the above five questions. You may find it helpful to share and discuss your concern with a colleague and if appropriate alert your line manager, as these can be difficult issues to deal with alone. **Should there be any concern that the adult may be at risk of harm, it is essential that the EMPPC – Adult Support and Protection Policy and Procedures are followed immediately.**

You should tell your line manager / supervisor why you are concerned, even if this is just a gut feeling, what you have done about it and what you plan to do about it. You must always ensure that the adult is safe, and record your concerns and actions.

Use your professional judgement in deciding what to do and when to do it. In doing so, you should always adopt a common sense approach and on a need-to-know basis.

### **How should I share information?**

- In every case, you must comply with your own service and / or agency's information sharing arrangements. These may take the form of policies, procedures, protocols, guidance etc. You should know how and where to access them.
- However if you share information you must ensure it is done safely and securely in line with your organisations existing information security procedures. If you are sharing information, you should only share information on a need-to-know basis. You should record your decisions in writing.

### **What should I be recording when I share information?**

When you are actively sharing information it is important you record this in the adults case file notes and / or any electronic system. The following should be recorded:

- What information you are sharing.
- Why you are sharing it.
- Who you are sharing it with.
- The date you shared the information.

### **Where you are requesting information, you should record**

- What information you need.
- Why you need this information.
- What you would be proposing to do with this information.
- Who else it may be shared with.

No matter how you are sharing information, you should ensure you are recording it accurately for future reference. This could be in a hard copy case file and / or in an electronic file. You should be recording your request and all responses received in accordance with your organisations procedures.

### **What if I decide not to share information?**

You should also be recording any circumstances where information is **not being** shared and the reasons for that. If you have requested and then been refused information you need to discuss this with your line manager / supervisor. You should also record any circumstances where there is a refusal to share information and the reason for that too. You should ensure that you record this clearly, accurately and concisely to prevent any misunderstanding and / or confusion on your part, on other practitioners part and for future reference. You should ensure that all this information is kept safe, secure and that there is no unauthorised access to this information.

### **If you decide not to share information, then you must ask yourself the following three key questions**

- What are my reasons for deciding not to share information?
- What harm could result if I do not share information?
- What are the implications for any other persons within the family/household this should also include child/children /young person / adult, for me and / or my service, agency and / or organisation if I decide not to share information?

This decision **not to** share information should be properly recorded, in hard copy case files and / or in an electronic file, for future reference.

## **8) Confidentiality and Consent to Support Adults (16 years and over)**

Effective early intervention necessitates appropriate and proportionate information sharing, as well as consideration of confidentiality and consent. For the purpose of this guidance, information sharing should be widely defined and interpreted as sharing and / or seeking and / or exchanging personal information and / or sensitive personal information in keeping with schedule 2 and schedule 3 of the Data Protection Act 1998 or articles 6 and 9 of the General Data Protection Regulation after 25<sup>th</sup> May 2018.

This document lays out guidance around sharing information for the benefit of the adults as well as the principles around confidentiality and consent to achieve best practice. This is a shared responsibility for all practitioners and managers working across the public, private and third / voluntary sectors.

- In adult protection situations where data sharing is a legal obligation. Note that the reasoning behind the decision to share data in these situations must be recorded in accordance with your organisations policy/procedures.

## **Not all information is confidential. Confidentiality is not an absolute right**

It is accepted that where there is a risk to an adult, which may lead to harm, that all confidential information in the best interests of the adult and / or in the public interest will be shared.

Any sharing of information should be **relevant, necessary, appropriate and proportionate** and go no further than the minimum necessary to achieve the public interest objective of protecting an adult's wellbeing, property rights and other interests.

### **Do I always need to seek consent?**

Recent advice from the (United Kingdom) Information Commissioner's Office has clarified what has been a misconception held by many in relation to the Data Protection Act 1998 and lawful processing.

Extract:

*"Where a practitioner believes, in their professional opinion, that there is risk to an adult that may lead to harm, proportionate sharing of information is unlikely to constitute a breach of the Act in such circumstances.*

*It is very important that the practitioner uses all available information before they decide whether or not to share. Experience, professional instinct and other available information will all help with the decision making process as will anonymised discussions with colleagues about the case. If there is any doubt about the wellbeing of the adult and the decision is to share, the Data Protection Act should not be viewed as a barrier to proportionate sharing.*

*In such cases, where information will be shared, it is considered best practice to obtain the adults consent and/or the consent of the legal proxy if appropriate.*

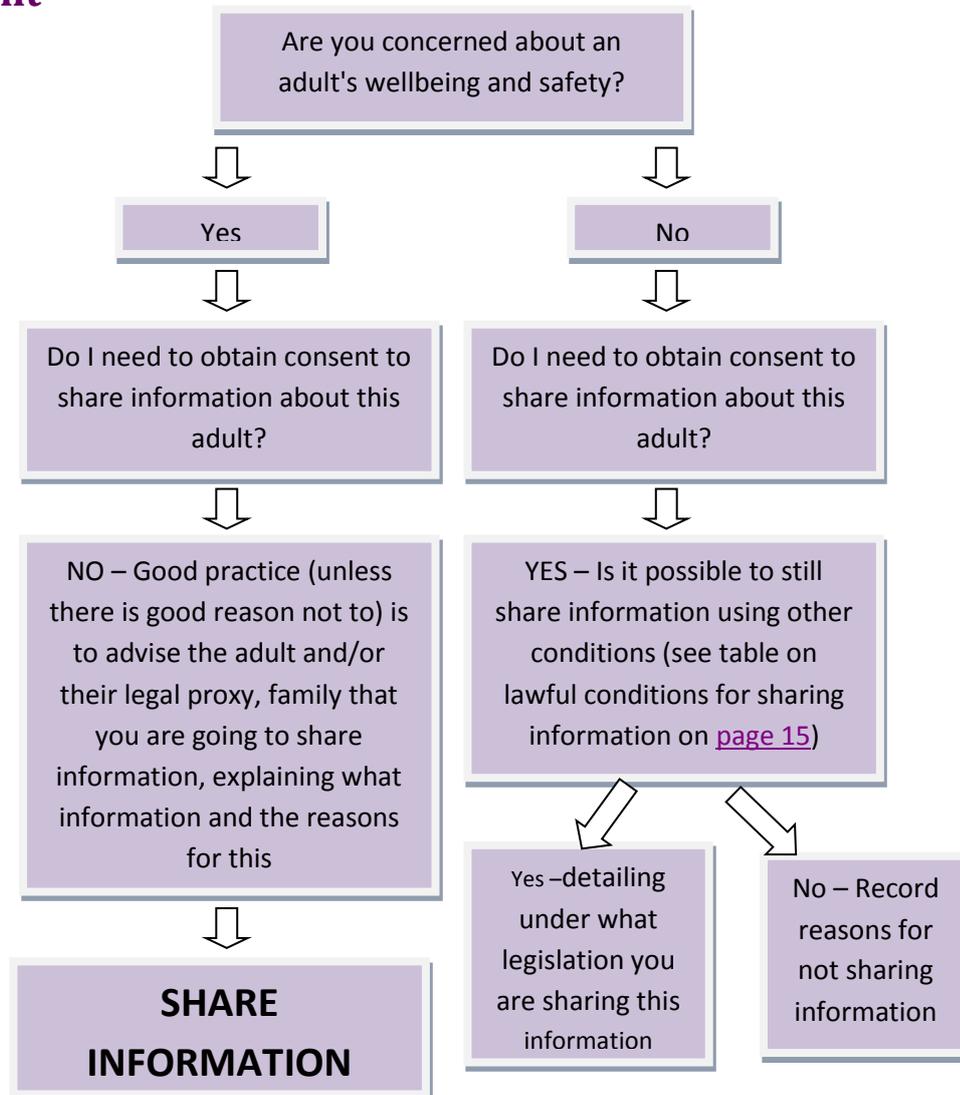
*In such circumstances, where this is not possible or that obtaining consent to share information may increase the risk to the adult then consent to share information is not required. If consent to share information is refused by the adult and/or their legal proxy they should be informed of the intention to share information and the reasons why, unless by doing so would further expose the adult to risk or hamper a police investigation.*

*You may be asked to justify that decision later, so best practice would be to record this in the adult's case file notes and / or in an electronic file as per your organisations procedures. Acting in the adult's best interest and / or in the public interest is a defence to an accusation of breach of confidentiality, provided it can be demonstrated that the information shared was necessary and proportionate"*

## When should consent be asked for?

Consent should only be sought when the individual has a real choice over the matter. There may be times when you are working with an adult and / or their family and you feel it necessary to share information. If this information does not relate to an adult support and protection concern then it would be appropriate to obtain consent to share information.

## 9) Consent



Consent should be:

- **Informed** – the individual (adult and if appropriate their family / legal proxy) must understand what is being asked of them and must give their permission freely. Information should be provided and of the possible consequences of withholding information.

- **Explicit** – the individual (adult and if appropriate their family / legal proxy) positively gives their consent for their information to be shared.
- **Revocable** – the individual must at any time be able to revoke their consent with the result that future information sharing cannot take place.

### **Who can give consent?**

Children from the age of Twelve to Fifteen

Children and young people from the age of twelve are presumed to have the full mental capacity to give informed consent and to take decisions in their own right.

If this is not the case, or you are in any doubt, you should seek consent from their parent/carer or other person with legal authority to act on behalf of the child or young person unless to do so would place the child at further risk.

Children from Sixteen to Eighteen

Parental rights and responsibilities largely cease when a child is aged sixteen. Parent/carers still have a responsibility to provide guidance to their child from age sixteen to eighteen.

### **What should I do if consent to information sharing is refused?**

Do not share and record the reason why.

### **What if consent is withdrawn?**

An adult (and if appropriate their family / legal proxy) cannot withdraw consent retrospectively. If incorrect information has been shared, the adult person has the right to ask for that incorrect information to be corrected. The receiving practitioner, service and / or agency should be notified accordingly and the information should be corrected.

### **Consent and Capacity**

There is no minimum age of capacity and all persons are assumed capable until determined otherwise. The question of whether a person has the capacity to make particular decisions should be regularly considered, including when care plans are being reviewed.

Consent is only valid if:

- The adult is legally competent – capable of consenting
- Consent has been given freely – no coercion
- The adult has been adequately informed and has understood the information given and the consequences of the information

- The adult has been informed that consent can be revoked at any time, however with no retrospective effect

Consent may not be needed if:

- Urgent / emergency situation – to save life, alleviate pain / suffering where the adult is unconscious and cannot indicate his or her wishes
- If there is a legal proxy acting on the behalf of the adult (Power Of Attorney / Financial/Welfare Guardian)
- In an adult protection situation where data sharing is a legal obligation
- Should still seek to give explanation and seek co-operation

### **Intervention Order**

- Sheriff Court has taken a decision to intervene in the adults affairs
- Should still give explanation and seek co-operation

An incapable adult means a person who has attained the age of 16 years and who is incapable by means of:

- a) Acting, or
- b) Making decisions, or
- c) Communicating decisions, or
- d) Understanding decisions, or
- e) Retaining the memory of decisions.

By reasons of mental disorder (mental illness, learning disability, personality disorder) or of an inability to communicate because of a physical disability (e.g. stroke). Every effort should be made to support the adult with their communication needs and can be made good by mechanical or human aid such as talking mats and sign language. An unwise decision does not necessarily indicate lack of capacity.

## 10) Lawful – Conditions for Processing Data (Data Protection Act 1998)

### Legislative context – Consent

The Data Protection Act 1998 and the General Data Protection Regulation provide specific conditions for processing personal information and special (sensitive) personal information respectively.

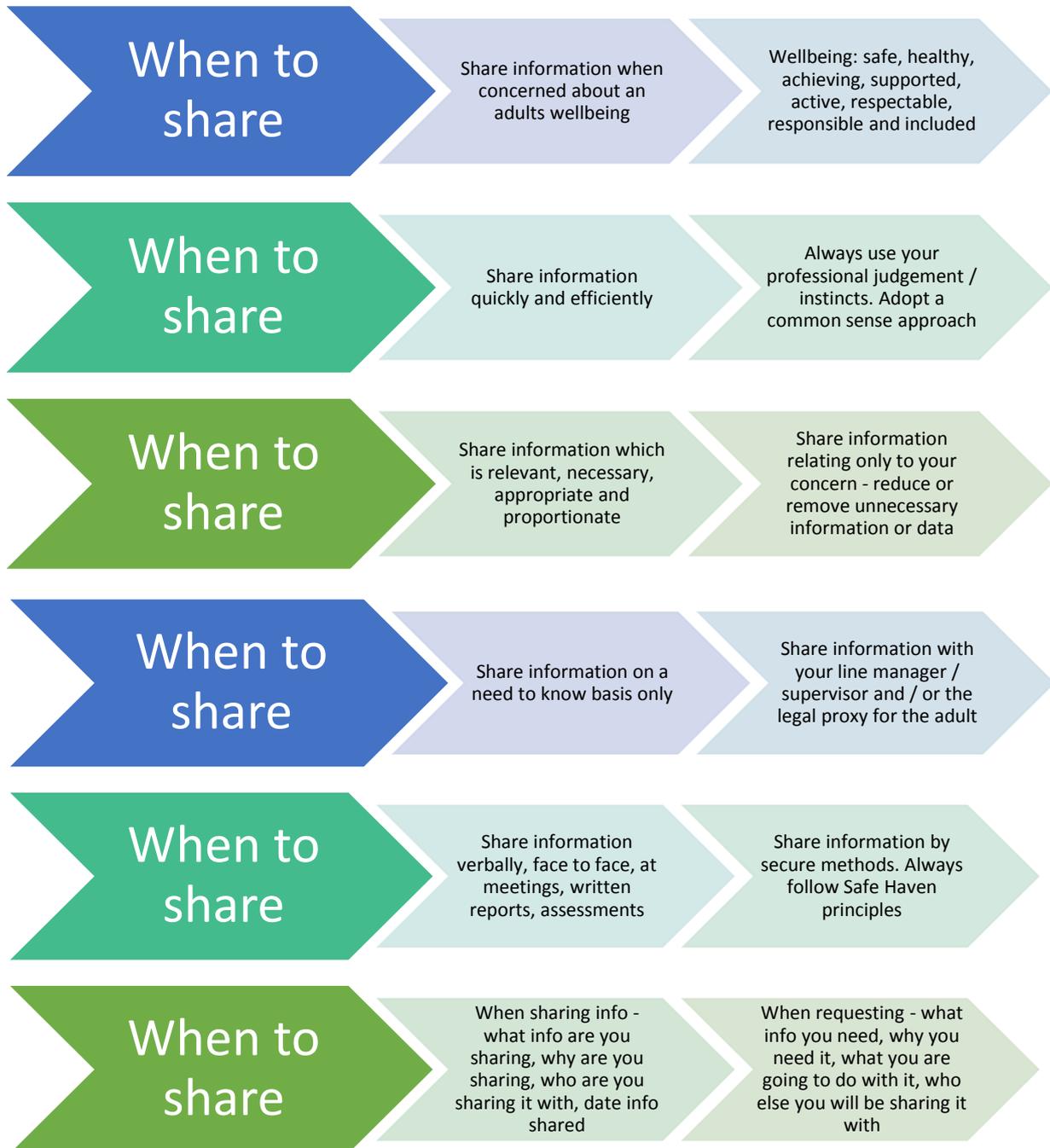
At least one criterion from the left hand column below **must be met** before processing personal information and at least one from each column for sensitive personal information.

Personal Data	Sensitive Personal Data
<ul style="list-style-type: none"> <li>➤ Consent</li> <li>➤ Contract</li> <li>➤ Legal Obligation</li> <li>➤ Vital Interests</li> <li>➤ Administration of Justice</li> <li>➤ Public function in the public interest</li> <li>➤ Legitimate interests of the data controller and third party but not prejudicial to individual – this condition will cease to exist on 25<sup>th</sup> May 2018</li> </ul>	<ul style="list-style-type: none"> <li>➤ Explicit consent</li> <li>➤ Employment law</li> <li>➤ Vital interests</li> <li>➤ Not for profit</li> <li>➤ TU / religious / political / philosophical groups</li> <li>➤ Already in public domain</li> <li>➤ Legal proceedings / advice</li> <li>➤ Administration of justice</li> <li>➤ Functions conferred by enactment</li> <li>➤ Anti-fraud activity</li> <li>➤ Medical purposes</li> <li>➤ Equal opportunities monitoring</li> <li>➤ Substantial public interest</li> </ul>

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## Appendix 1 – Information Sharing Summary

A useful summary of the key considerations for all practitioners when considering when to share information.



## Appendix 2 – Legislation and Policy Context

Information sharing, confidentiality and consent are underpinned by a UK Government and / or Scottish Government, Legislative and Policy Framework. Practitioners may find the following further reading useful:

### Key Legislative Framework:

- Adults with Incapacity (Scotland) Act 2000
- Mental Health Care and Treatment (Scotland) Act 2003
- Adult Support and Protection (Scotland) Act 2007
- Forced Marriage (Protection and Jurisdiction) (Scotland) Act 2011
- Children and Young People (Scotland) Act 2014
- Civil Contingencies Act (Scotland) 2004
- Social Work (Scotland) Act 1968
- Social Work (Scotland) Act 13ZA 1968
- Age of Legal Capacity (Scotland) Act 1991
- Children (Scotland) Act 1995
- Human Rights Act 1998
- Data Protection Act 1998
- Freedom of Information (Scotland) Act 2002
- Counter Terrorism and Security Act (2015)
- Vulnerable Witness (Scotland) Act 2004
- Prohibition of Female Genital Mutilation (Scotland) Act 2005
- Anti-Social Behaviour Crime and Policing (Forced Marriage) (Scotland) Act 2014

- Community Care and NHS Act 1990
- Self-Directed Support (Scotland) Act 2013

**Key Policy Framework:**

- UN Convention on the Rights of the Child (1989)
- Common Law and Statutory Obligations of Confidence (2004)

## Appendix 3 – Caldicott Principles

### ***Principle 1 – Justify the purpose(s)***

Every proposed use or transfer of patient-identifiable information within or from an organisation should be clearly defined and scrutinised, with continuing uses regularly reviewed by an appropriate guardian.

### ***Principle 2 – Don't use patient-identifiable information unless it is absolutely necessary***

Patient-identifiable data items should not be used unless there is no alternative.

### ***Principle 3 – Use the minimum necessary patient-identifiable information***

Where use of patient-identifiable information is considered to be essential, each individual item of information should be justified with the aim of reducing identifiability.

### ***Principle 4 – Access to patient-identifiable information should be on a strict need to know basis***

Only those individuals who need access to patient-identifiable information should have access to it, and they should only have access to the information items that they need to see.

### ***Principle 5 – Everyone should be aware of their responsibilities***

Action should be taken to ensure that those handling patient-identifiable information, (both clinical and non-clinical staff) are made fully aware of their responsibilities and obligations to respect patient confidentiality.

### ***Principle 6 – Understand and comply with the law***

Every use of patient-identifiable information must be lawful. Someone in each organisation should be responsible for ensuring that the organisation complies with legal requirements. The Information Governance Review, April 2013 (known as Caldicott 2), added a 7<sup>th</sup> Principle.

### ***Principle 7 – The duty to share information can be as important as the duty to protect patient confidentiality***

Health and social care professionals should have the confidence to share information in the best interests of their patients within the framework set out by these principles. They should be supported by the policies of their employers, regulators and professional bodies.