Scottish Borders
Multi Agency

Information Sharing Protocol

Version & Revision Control

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0.3	21/04/05	Jackie Stephen	Geoorge Ironside Veronica Ross Dawn Moss Linda Jackson Jan Spence Dave Arkless	Changes from workshop 21/4/05
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0.6	23/06/05	Jackie Stephen	NHSB & SBC staff consultation June 2005	Appendix 1 – Children's Change to text 6.1
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1.0	9/11/06	Jackie Stephen		Final Version for first Release

Schedule of Partner Agencies

The Agencies listed here have agreed to adopt and adhere to the contents of this Protocol.

Signed :	**Signed:**
Date :	**Date:**
Name:	**Name:**
Designation :	**Designation:**
On behalf of NHS Borders	**On behalf of Scottish Borders Council**

1 Background

1.1 A partnership of agencies has been established in the Borders to encourage joint working whereby the benefits of shared resources and expertise can benefit the health and wellbeing of the population in the Scottish Borders.

1.2 The sharing of personal information is necessary to facilitate the provision and delivery of services in a coordinated and seamless manner to the user avoiding duplication of effort in many cases, and to meet the statutory duties inherent to some agencies. There may be times in cases of suspected /alleged abuse, or other identified risk when a duty of care will override other factors and it is appropriate to share information. Sharing of information is also needed by practitioners to ensure that a joint working approach in the Borders area becomes a reality.

1.3 The lawful, professional and proper control of such personal information by the agencies is extremely important to the success of care/service provision.

1.4 Equally important is maintaining the confidence and valid expectation of individuals that all personal information whether in paper or electronic format, held by any partner agency is protected and used appropriately.

1.5 This requires the creation and implementation of essential technological and organisational measures to provide the controls to allow only appropriate sharing of information. These measures are detailed within this protocol.

1.6 This protocol has been developed to enable the sharing of information about an individual between partnership agencies and professional disciplines.

2 Scope

2.1 This protocol covers the agreed general principles for information sharing between all partner agencies that have signed up to its adoption and use within their own organisation. These agencies may include but is not limited to the relevant Local Authority and its sub organisation entities, the relevant NHS organisation, and voluntary sector or private service providers.

2.2 It covers all population groups and individuals where access to information is necessary and legitimate as part of their care or provision of services by one or more of the partner agencies.

2.3 It is confined to the purposes defined in this document and does not include other requests for information outside the scope of this protocol. E.g. When Police request information on whether an individual has been treated. These types of requests are covered in separate agency policies.

2.4 Where specific additional principles or procedures are required for a particular group these exceptions are detailed in the appendixes at the end of this protocol. These are supported by the necessary guidance and procedures for service users and practitioners on how the principles are to be implemented.

2.5 **This protocol requires that any sharing of information, except in specific, exceptional or limited circumstances, as allowed by law, is with the explicit given consent of the service user and that confidentiality of information is**

maintained at all times.

2.6 Within this document, the capacity of the individual to give, modify or withdraw consent is presumed. The impact of incapacity on any procedures is addressed explicitly elsewhere in this document (see Adults with Incapacity information in Appendix 1). This document does not address how to assess or make decisions on capacity.

2.7 This protocol provides a written, formal agreement between the agencies as identified and recognised by the signatures of the authorised and designated officer from each agency.

2.8 Upon signing, these agencies become members of the partnership of agencies. Any subsequent organisations arising out of these recognised partnership agencies, as may occur due to national or local re-organisation directives, will also be bound by this protocol.

2.9 This protocol follows the Scottish Executive Health Department Information Sharing Protocol model and Gold Standard and will follow document version control to ensure changes are able to be audited.

3 Objectives

3.1 **INFORMATION MANAGEMENT**: To legitimately and securely manage the sharing and exchange of information between agencies in accordance with legislative and professional requirements.

3.2 **PURPOSE**: To define the specific purposes, for which agencies hold and have agreed to share information in order to fulfil their statutory and/or professional responsibilities to protect, support and care for service users.

3.3 **ACCESS**: To define how such personal information will be held within each agency, how it will be shared and who can access it.

3.4 **PUBLIC INFORMATION**: To determine the method whereby individual service users are advised as to what information is held, and under what circumstances that information would be shared, with which other agencies, how this would be done and who would have access to it.

3.5 **SECURITY:** To describe the security provisions in place for information sharing which safeguard an individual's confidentiality

3.6 **IMPLEMENTATION & MONITORING**: To define the implementation and monitoring processes for this protocol within the partnership agencies.

3.7 **REVIEW & CHANGE**: To identify when this protocol will be reviewed, by whom, and how changes will be authorised and auditable.

4 General Principles of Data Sharing

4.1 Although there is no statutory requirement to share information, the partnership agencies, as public authorities, have various powers that are instrumental to them carrying out their activities. Often implicit in these powers is the sharing of information.

4.2 Agencies must ensure that they are able to work effectively and efficiently together to guarantee that the services provided will meet the needs of each individual. This means ready access to the necessary information about those individuals and other partner agencies involved in their care, support, and protection is essential. Such sharing requires to be done in a safe, secure and confidential manner in which the individual service user can have confidence.

4.3 Person identifiable information should not be transferred or shared with any third party without agreement of the other signatories to this protocol, (see appendix 4 on bulk transfer of information).

4.4 Prior to any new agency signing the protocol their details should be passed to the Data Protection Office for confirmation of their correct and current Notification status

4.5 Caldicott

- **Non NHS organisations must recognise the requirements that Caldicott places on NHS organisations. This means that non-NHS partner agencies must ensure that any information requests are dealt with in a way compatible with these requirements, i.e that only appropriate and agreed staff will have access to shared information. Caldicott Guidelines are not to be misused by any partner organisation as an obstacle to the sharing of information.**

4.6 Confidentiality

4.6.1 All partnership agencies must recognise the duty of confidentiality and are obliged to safeguard an individual’s personal information and privacy at all times. The duty of confidentiality is dictated by legislation, national and local policies, employment contracts and professional codes and standards. Any breach of confidentiality may provide grounds for complaint against the individual employee and may result in disciplinary action.

4.6.2 The essence of a breach of confidentiality is when unauthorised use of the shared information is detrimental to the person who gave it in the expectation that it would remain confidential.

- Confidential Information is information that has been shared with another person with the necessary ‘quality of confidence’. E.g. is of content which would be reasonably expected to be confidential

and

- The information must have been imparted in circumstances imposing an obligation to keep the information confidential. E.g. clinical interview.

4.6.3 Authorised use is the basis for obtaining consent. I.e. if you gain consent from an individual about their personal information you have gained authorisation i.e. consent.

4.7 Consent

4.7.1 Consent to disclose information must be sought from the person concerned unless there are statutory grounds that justify overriding the requirement to gain the person's consent.

4.7.2 Any decisions to override consent must be recorded stating the reasons and justification so that this can be audited and if necessary defended.

4.7.3 Each individual must be fully informed about the possible and probable uses of the information held on them.

4.7.4 Once obtained, informed consent will be recorded and adhered to by all partnership agencies.

4.7.5 Where consent is withheld, this will be respected by partnership agencies. Withholding consent may impact on the ability of the partner agencies to provide services and this must be fully explained to the individual.

4.7.6 Where the individual is deemed or assessed as not having the capacity to consent or due to other factors is unable to give consent, guardians and professionals responsible for providing that persons care may be asked to give consent on their behalf.

4.8 Specific Purpose

4.8.1 It is not anticipated that any partner agency will need to disclose all the information that it holds. Consideration must be given to what categories of information will be required.

4.8.2 Information obtained under this protocol cannot be shared with other parties that are not part of this agreement, unless explicit consent has been received to do so e.g. for provision of a service by a private or voluntary organisation on behalf of one of the partners.

4.8.3 Information can only be sought and shared between relevant agencies for a specified purpose as established under the agreed procedures covered in this protocol and appendices. Specific purpose and appendices?

4.8.4 Information obtained under this protocol should not be regarded as information for general use within any of the partner agencies and must be accessed and used on a strictly ‘need to know’ basis for the specified purpose.

4.8.5 The minimum amount of identifiable information for the specified purpose will be shared.

4.8.6 Employees of partnership agencies will be made aware of the conditions under which information is shared and of their obligation to share only appropriate information covered under the conditions of this protocol. This will include staff briefings, training and written material.

4.8.7 The individual or their legally recognised representative has the right to access the information held on them within an agency and be able to correct any factual inaccuracies, unless there are statutory grounds for restricting access to information related to them. In this case an explanation of these restrictions must be offered to the service user.

4.8.8 Each organisation will have in place a policy that determines how the individual's requests for access will be dealt with.

4.8.9 Partner agencies will consider and develop an appropriate joint policy on dealing with individuals request for access to information contained within a share storage area or integrated case note files.

4.9 Language and Jargon

4.9.1 Partner agencies should wherever possible eliminate the use of professional jargon, abbreviations and acronyms that may not be familiar to others, except where this relates specifically to medical diagnosis and terminology where proper meaning is essential.

4.9.2 Best practice would ensure that Partner Agencies had in place a set of guidelines for staff on how to record information and that these are fully implemented by their staff. E.g. SBC Recording Guidelines [2004]

4.9.3 Any acronyms should be initially explained in the text to ensure understanding by all parties. The information should be identified as being factual or professional opinion.

4.10 Complaints

4.10.1 Each partner agency is required to have an effective complaints procedure to address any issues relating to disclosure of information.

4.10.2 Partner agencies will consider and develop if appropriate a joint complaints procedure relating to shared information.

4.10.3 Individuals should be made aware of this complaints procedure and not feel intimidated by making a complaint on how their personal information has been shared or used

5 Key Legislation & Documentation

- A list of relevant legislation and links to useful documents are included in Appendix 6.

6 Purpose for which Information will be shared

6.1 The following purposes have been agreed as justifiable under this protocol, for the transfer, exchange and sharing of personal information between the recognised partnership agencies.

- To improve the quality and delivery of services to people within Borders.
- To produce consistency of services and information
- To provide professionals with the information needed to deliver high quality consistent services
- To minimise duplication of information gathering by partnership agencies thereby reducing the duplication of giving information by individuals.
- To support out of hours care provision for the Borders Community.
- To support joint planning, commissioning of care services and effective use of resources.
- To support statutory reporting and notification.
- To assist individual partnership agencies with the management of current services and for planning future service provision and information.
- To support national initiatives on multi-agency working and information exchange.
- To enable statistical analysis of anonymised data required locally and/or nationally.
- To enhance the robustness and effectiveness of systems which are required to help support, protect or care for service users
- To assist in the prevention, investigation and intervention of situations where alleged abuse is taking place.
- To maximise the health and safety of clients and staff delivering services.

6.2 This protocol will continue to be applicable where all the partnership agencies agree that

a) Further sharing of information is beneficial and
b) They will adhere to the general principles outlined in this protocol.

7 Disclosure of Personal Information

7.1 Obtaining Consent

7.1.1 Consent must be obtained in order to share personal information with other partnership agencies. It should be obtained, ideally at first contact, by the person who gathers the information to be shared and/or who needs to share the information in order to provide care or services.

7.1.2 When consent is given it must be informed, specific and freely given. Consent should be obtained;

- In a sensitive manner

- As soon as is practicable following first contact and ideally before service delivery

- By giving a full explanation of what information may be shared, with whom and for what purpose which allows the prospective service user to make an informed decision about consent. This may include that personal data may be anonymised for statistical purposes.

7.2 It must be explained that the wish for information not to be shared, can be overridden in some circumstances, essentially for statutory reasons or because of concerns about someone's health and safety. This is particularly relevant to Criminal Justice professionals who work with mentally disordered offenders who may pose a serious risk of offending and who are a risk to other vulnerable adults and children but are also patients in their own right. (See Appendix 5 for further guidance)

7.2.1 There will be a range of support materials or leaflets available in a variety of formats and languages to assist with explaining consent to prospective service users of each Partnership agency.

7.2.2 There will be occasions it is deemed a person is unable to fully understand the implications of giving or withholding consent or is unable to make an informed decision regarding consent (See Appendix 1 and 4). Each partnership agency should have procedures in place which specify the circumstances under which agencies can disclose information without consent and ensure staff are appropriately trained

7.2.3 Operational guidance for each section or department will be developed in conjuction with each section or department once the general protocol is implemented and will give clear and explicit guidance to staff in relation to putting the protocol into practice.

7.2.4 Relevant data can be retained, for only as long as is necessary to provide the services required by the individual service recipient. In practice for both NHS and Social Care providers this is likely to be for longer than the minimum retention periods agreed for each partner organisation. Arrangements should still be made to regularly review what is held and to justify retention where it has been agreed.

8 Recording Consent

8.1 Recording consent will be consistent with partner agencies' existing policies and procedures and best practice for record keeping.

8.2 Under normal circumstance a signature should be obtained on an agreed joint consent form to record that consent has been given. The consent form should be kept in the service users file within the lead agency.

8.3 Where it is not possible to obtain a signature, practitioners must be able to demonstrate that sufficient information was given to the individual, and/or their legally recognised representative, to enable them to give informed verbal consent. This should be recorded by the professional who asked for consent in the individual's case file recognising that verbal consent was given.

8.4 Where consent has been withheld, the reason (or 'reason not known') should be recorded in writing along with the status of the consent. Recording consent or the lack of it must be shown in a way that is transparent to anybody reading the record.

8.5 Each partner agency should have the facilities, whether manual and/or electronic to be able to manage consent i.e. be able to record, monitor, review and update the status of the consent.

9 Duration and Review of Consent status

9.1 Consent is valid for the purposes for which it was given until it is withdrawn.

9.2 It would be best practice to review consent status with the individual when further sharing for the same purpose is required, however a minimum standard would be that at the very least consent status would be reviewed annually for active cases. Each service group may determine their own standards for reviewing consent which in line with best practice guidelines (as per 7.2.3). This would be highlighted when training and informing staff

9.3 When sharing is required for an additional purpose, the consent status should be reviewed with the individual and amended or a new consent sought.

10 Disclosing Information when Consent has been given

10.1 Prior to disclosing personal information to another partnership agency, staff must ensure that a valid consent exists.

10.2 Partner agencies will ensure they maintain accurate records about the disclosure of information originating from their files. The following must be recorded:

- Whether the information was shared with or without consent of the individual
- The reason for the disclosure
- What information has been disclosed and to whom
- The source of the data disclosed and the date of disclosure
- This will be recorded on the relevant IT or paper systems as part of the client or patient record.

10.3 Each agency must have in place documented procedures that specify who is responsible for ensuring this is done. This person should also be responsible for the collection, processing, updating and destruction of the information and any procedures for obtaining updated information.

11 Disclosing Information without consent

11.1 **The Data Protection Act (1998) is not a barrier to disclosures without consent in appropriate circumstances**.

11.2 Individual partner agencies will have local procedures in place which state the circumstances under which their staff can disclose information without consent. These take account of current legislation, relevant local/national guidance, professional standards and **risk to the individual of not disclosing information**.

11.3 Staff should refer to and operate within these organisational policies and their relevant professional codes when disclosing personal information without consent, taking account of the potential risk to an individual of not disclosing information.

11.4 Professional Codes are **NOT** a barrier to sharing information where it is in the interests of the individual or the public.

11.5 If information is disclosed and it cannot be justified, both individual staff members and/or partnership agencies are at risk of prosecution and/or compensation.

11.6 Best practice suggests that individuals should be told if information about them is being disclosed without their consent.

11.7 It is both a requirement of the partner organizations and best practice to record in writing the reasons for disclosure and the evidence justifying this.

12 Staff Guidance on Consent Seeking

12.1 Training and Operational Guidance

12.1.1 To support staff each partnership agency should provide appropriate training and guidance materials which cover

- The principles upon which this Protocol is based
- The need to gain consent and the consequences of not doing this.
- Who is trained to seek consent and how their involvement should be initiated?
- Who is able to take a decision on behalf of another person?
- The circumstances under which information may be disclosed without consent.
- Who can authorise the disclosure of information without consent and how this authority should be requested? E.g. Line manager is informed and decision is recorded in writing
- The records which must be kept of this process.
- The procedures for recording and storing consent to share information.

- The procedures for recording limitations of consent to share.

- When consent expires and in which circumstances consent is invalidated.

- The procedures to be followed when consent is limited.

- Relevant professional codes

12.1.2 Heads of Service and Senior Managers within each partner agency are expected to become familiar with this policy, produce additional operational guidance notes if required and provide staff with ad-hoc guidance on different scenarios as they arise.

12.1.3 Staff must be made aware of this policy during any Induction programme and be advised of how to access training in this policy.

12.2 Register of persons trained in this protocol

12.2.1 Each partner agency will be expected to keep a register of staff that has been trained in the use of this protocol. This register will include the name, contact information and role of staff who

- Have been trained in the use of this protocol and its application for Information Sharing between partnership Agencies.

- Staff who have not yet undergone training within the Information Sharing Protocol will still be able to obtain consent and share information

- A rolling programme of training for all staff will be developed and rolled out following adoption of the Protocol

13 Access & Security

Each partner agency must confirm that they have a formal security policy in place which addresses the standards in this section PRIOR to the exchange of person identifiable information in order to protect individuals from misuse of information.

13.1 Transfer of Personal Information

13.1.1 The Partnership agencies are required to ensure that information that can identify individual service users is transferred and shared in a secure manner.

13.1.2 Access to person identifiable information must be restricted to staff who require it to perform their duties in connection with the care of an individual for one or more of the purposes listed in this protocol.

13.1.3 It is essential that requests for personal information about service users be accompanied by sufficient information to ensure that the person can be clearly identified - and subsequently 'matched' with any existing data held in the same or other partner agencies.

13.1.4 Electronic computerised systems containing or used to transfer person identifiable information must be secured by individual user logon accounts.

13.1.5 Passwords must not be given to anyone other than the nominated user(s).

13.1.6 An electronic system should not be left unattended and active to minimise the opportunity of it being accessed by an unauthorised user.

13.1.7 Policies and procedures should be in place to protect the physical environment where person identifiable information and/or confidential information is stored whether on paper or electronic computerised systems. This includes portable information formats and devices such as CD's, USB Devices, discs laptops, mobile personal devices etc.

13.1.8 Electronic transfer of personal information will only be allowed across secure networks.

13.1.9 Fax transfer of personal information should be avoided. Where it is necessary, staff should follow their agency procedures to ensure secure transfer by fax, between safe havens.

13.1.10 In urgent cases, the telephone may be used to request or provide information about an individual. Staff should ensure that they have taken appropriate steps to identify the person requesting and receiving the information and that that person has a valid purpose for doing so and is authorised to do so. Face to face communication is also subject to these conditions.

13.1.11 Written communications to share information should be titled “addressee only to open” and addressed to the designated person within the organisation.

13.1.12 The intended recipient should be contacted to advise them of the despatch of the information and the expected timescale for it to be delivered to them. It should be received unopened by the recipient.

13.1.13 Where an expected written communication does not arrive within normal mail times the sender should be notified.

13.2 Use of Personal Information for purposes other than agreed

13.2.1 Whilst it is recognised that staff may fulfil a number of roles within their organisation any privileged information they are able to access for one role should not be used in the performance of their other roles.

13.2.2 Service user information should be used only for the purpose specified at the time consent is obtained. It is therefore a condition of access that confidential information should not be used for any other purpose without the consent of the data controller and the data subject.

13.2.3 Partnership agencies that wish to use confidential information for any other purpose than was consented or who wish to disclose the information to any person other than those authorised to receive it, must submit a formal application to the data owner. It is the responsibility of the data owner to obtain the consent of the patient /client to further use of that information or to decide whether the reason the information is required justifies disclosure without consent.

14 Access to Service User Data

14.1 Where more than one partner agency have staff operating in the same care team they must agree between them what systems will be used for storing Service User Personal data required by that team. This might be the case/file management system of one or the other of the agencies or may alternatively be in a shared data store.

14.2 Where the records of a joint care team are to be stored on a single agency computer system, staff in that team, employed by one of the other agencies that require access to the system must be advised of and agree to the following;-

- That the information stored on the system is confidential

- That access to the system is only given to the staff member to enable them to carry out their function within the joint care team and cannot be used for any other reason.

- That the member of staff is only authorised to access records on the system relating to Service Users who are allocated to that staff member or team. No other records should be accessed or any attempt made to access them.

14.3 Breaches of access or attempted breaches will be subject to disciplinary action under the employing organisations disciplinary procedure.

15 Protocol Management & Operation

15.1 Partner Agency Pre-requisites

15.1.1 Each partner agency will have a valid Data Protection notification with the Information Commissioner.

15.1.2 Each partner agency must have relevant information to share or have a legitimate need for the shared information.

15.1.3 Each partner agency must have in place a process to record and deal with breaches of this protocol.

15.1.4 Each partner agency must have in place an appropriate security policy that supports the aims of this protocol.

15.2 Formal Approval, Adoption & Implementation

15.2.1 Each partner organisation is required to formally approve this protocol. Individual procedures applicable to each partnership must be authorised by the appropriate agency.

15.2.2 Formal adoption of this protocol will follow the signing of this document by the head of each Partnership organisation that is able to execute legally-binding documents on behalf of their organisation.

15.2.3 Partner agencies should draw up operational procedures in support of implementing this protocol for their particular client groups.

15.2.4 The head of each service area within a partner agency will be responsible for ensuring that operational procedures are in place and are followed in order to implement this policy for their particular client group.

15.3 Distribution of Policies and Procedures

15.3.1 This protocol and the relevant procedures require to be introduced to staff, through a programme of training. This training can either be delivered jointly between partnership agencies or independently by each agency.

15.3.2 Copies of this protocol and the relevant procedures will be circulated to appropriate staff in line with each agency's distribution arrangements.

15.4 Monitoring and Reviewing

15.4.1 All procedures supporting this protocol will be subject to regular formal review. Any major changes which are proposed may require legal advice before changes are made and enacted.

15.4.2 Each procedure will set out the particular arrangements for its review. These will include details of: -

- The body responsible for reviewing and agreeing changes.
- The date of the initial review and the review frequency
- The Party or individual who will co-ordinate the review.

15.5 Reporting Breaches of Protocols

15.5.1 Following the introduction of new joint working arrangements and until the first review, all breaches of this protocol will be logged, investigated and the outcome noted. A review will take place regarding any changes required to what is defined as a breach.

15.5.2 Consequently agencies must have in place, a system where complaints regarding the inappropriate use or disclosure of information are reported to the body responsible for the security of that information. This complaints procedure should be accessible to members of the public should they wish to report alleged breaches of confidential information.

15.5.3 Staff will be required to report responses and behaviour, which they believe, are not in accordance with the procedures.

15.5.4 The following types of incidents will be logged

- Refusal to disclose information.

- Conditions being placed on disclosure.

- Delays in responding to requests.

- Disclosure of information to members of staff who do not have legitimate reason for access.

- Non delivery of agreed reports.

- Inappropriate or inadequate use of procedures e.g. insufficient information provided
- Disregard for procedures.

- The use of data/information for purposes other than those agreed.

- Inadequate security arrangements.

- Actual or attempted security breach by an external party i.e. hacking.

15.5.5 Any staff member who becomes aware that the agreements and procedures set out in this protocol are not being adhered to, whether in their own or another of the Partnership agencies, should raise the issue with the line manager responsible for the day to day management of the procedures.

15.6 Breaches as alleged by members of the public

15.6.1 Breaches as alleged by member of public must be investigated and the relevant organisational policy for such breaches must be followed. Refer to Appendix 5.

16 Contractual Agreement

16.1 The Partnership Agencies to this protocol accept that the standards laid down in this document will provide a secure framework for the sharing of information between their agencies in a manner which complies with their statutory, legal and professional responsibilities.

16.2 As such all agencies undertake to

- Implement and adhere to the procedures and structures set out in this protocol.

- Ensure that all individual agency procedures established between the Partnership Agencies for the sharing of information relating to the population of the Borders are consistent with this protocol.

- Ensure that where this protocol is adopted, no restriction will be placed on the sharing of information other than those specified in this document or individual procedures.

Appendix 1 – Adults with Impaired Capacity

The principles of consent (information, freely given, and capacity to give consent) apply to all individuals. It is important to be aware that most people suffering from a mental illness (including people with dementia) or learning disability retain the capacity to make most healthcare decisions for themselves. An individual's capacity to reach a decision on their healthcare will depend on the decision in question, their intellectual state at the time and the nature of their disorder.

Adults with Incapacity (Scotland) Act 2000

In Scotland, approximately 100,000 people over the age of 16 have difficulties in taking decisions for themselves because of mental disorder or a communication disorder due to a physical and/or learning disability. Application of the Act's principles and provisions should ensure that these adults receive equity of access to care.

The Act defines incapacity as being incapable of:

- acting or
- making decisions or
- communicating decisions or
- understanding decisions or
- retaining the memory of decisions

The cause of the incapacity must be mental disorder or inability to communicate because of a physical disability. Mental disorder includes mental illness, personality disorder, learning disability and other causes of mental impairment. You should be aware that this definition includes adults who are unconscious and on a ventilator in Intensive Care Units because of illness or injury.

There are many people with a learning disability who may have varying degrees and levels of understanding and who would not in any way regard themselves as having a mental disorder. Many people with a learning disability also have very complex health needs, including physical disability. This can affect both their understanding and the ability to communicate effectively, unless careful and planned assistance is given to help them.

If you can overcome or improve on the disability by human or mechanical support, then it is a requirement of the Act to do so. This can include simple measures such as ensuring the adult is wearing their glasses and hearing aid or providing a quiet and distraction-free environment. You may need to involve other people, including speech and language therapists, signers or interpreters, to help bridge the communication gap.

People with a learning disability can often achieve a level of understanding that you might not have expected, providing that information is well presented by experienced people. Sometimes mechanical aids are also helpful here.

Principles

The Act sets out principles that must be observed. All decisions made on behalf of an adult with incapacity must:

- benefit the adult
- take account of the adult’s present and past wishes and feelings
- take into account the wishes of the nearest relative, primary carer, proxy and relevant

others, where it is reasonable and practicable to do so
- restrict the adult’s freedom as little as possible while achieving the desired benefit

You should note that capacity is specific to the situation. This means that an adult may be capable of reaching a decision on some aspects of their care, but incapable in terms of handling decisions about more complex aspects.

Codes of Practice on the Adults with Incapacity (Scotland) Act 2000 have been published and further information about the Act can be found on the Scottish Executive Justice Department’s website (www.scotland.gov.uk/justice/incapacity).

When someone refuses examination

You may be faced with someone who refuses to be examined and you think that his or her refusal may be because of a mental disorder. This can be a difficult situation to deal with because it may happen without much warning and in surroundings such as the person's home or an Accident and Emergency Department. Sometimes you may become involved after the person has been taken into police custody.

If the person refuses to talk to you, or to be examined, it may be because they are seriously mentally ill and are a potential risk to themselves and to others. If so, you may have to consider whether it is appropriate to use the Mental Health Act. If the person is unwilling or unable to consent to examination then you may have to obtain information about the patient from other sources. This could include relatives and friends of the person, police officers or other people involved in the current situation. Part V of the Mental Health Act describes the conditions that must be satisfied before emergency detention can take place.

The Mental Health (Care and Treatment) (Scotland) Act 2003

This Act will come into effect on a staged basis. In relation to consent, it updates mental health legislation in Scotland in two important ways. The first change lies in the area of urgent treatment in emergencies. Part X of the 1984 Act does not give authority to treat a patient detained on a Section 24 (Emergency) Order. By contrast, Section 2(4) 3 of the 2003 Act does allow for medical treatment to be given to a patient who does not consent or is incapable of consenting to that treatment even where that patient is detained because of an Emergency Detention Certificate (issued under Section 36 of the 2003 Act).

Urgent treatment can only be provided where the purpose of the treatment is to;

- save the patient's life
- prevent serious deterioration in the patient's condition
- alleviate serious suffering on the part of the patient
- prevent the patient from behaving violently or from being a danger to himself or others

This treatment must not be hazardous or irreversible. The second important way in which the 2003 Act updates Scottish mental health legislation is through the introduction of a set of principles known as the Millan Principles which you should apply when carrying out functions under the Act. From the point of view of consent, the most relevant principles are non-discrimination, informal care and participation. The Millan Principles will have an impact on many health professionals in NHS Scotland whether or not you are working in the field of mental health.

Appendix 2 - Children's Services

Parental Consent

Under the Children (Scotland) Act 1995 a parent with the right to consent for a child is the mother (unless her parental rights have been removed by a court) and the father of the child if he is or has been married to the mother either at the time of conception of the child or subsequently, or where he is not married to the mother he has been granted rights and responsibilities for the child by the court.

Other adults or the Local Authority may be granted rights and responsibilities by the court, this is called a "Parental Responsibility Order" (PRO). A person can also have parental responsibility if he registers as the child's father from May 2006 under the Family Law (Scotland) Act

It is considered sufficient to obtain the consent of one parent if both are in agreement. If the child has capacity and a parent also agrees to the consent then this is sufficient. If the child lacks capacity and the parents disagree then there is a need to consult the court in order for arbitration to take place and a decision on consent to be made. In extreme cases the court may act in the child's best interest to grant consent for an individual purpose. The court may also decide to examine the need for a PRO to be made to another adult or Local Authority to ensure that the child's best interests are met.

Consent should always be obtained when the participants understand the issues appertaining to the decision that needs to be made. Informed consent is the requirement of the law and of safe practice.

Parental Rights and Responsibilities

A person or Local Authority who has parental rights and responsibilities in relation to the child has responsibility to act as that child's legal representative.

Who has parental rights and responsibilities?

- the child's mother (whether she is married to the father or not) unless these rights have been removed by a court
- the child's father if:
    - he is married to the mother either when the child is conceived or afterwards
    - he is not married to the mother but the mother has agreed he should have parental rights and responsibilities (and this is registered in the Books of Council and Session)
    - he is not married to the mother but the Sheriff Court or Court of Session has made an order giving him parental responsibilities and parental rights
    - he is registered as the child's father on the UK birth register (after 4th May 2006)

- a guardian who has been properly appointed (in the event of the parent's death)

- Other adults can hold full parental rights and responsibilities only if this is decided in court.

- Local Authority if granted by the court

What about parents who are separated or divorced?

The law aims to make sure that parents who are separating or divorcing are both involved in bringing up their child and continue to share their responsibilities towards the child. This means that in the event of separation or divorce both parents continue to have responsibilities and rights towards the child.

Removal of Parental Rights and Responsibilities

Parental rights and responsibilities can only be removed by order of the Sheriff Court or the Court of Session.

Appendix 3 – Multi Agency Meetings - All Client Groups including Children

Multi-Agency Case Conferences / Meetings

Where multi-agency groups meet together to discuss 'named' children / adults i.e. the child/person or a family member's name will be used or could be identified during the discussion, then consent must be obtained from the person/ parents/carer. Good practice would dictate that consent should be sought from both parents unless in exceptional circumstances. This can be implied, verbal or written, although again in terms of evidencing decisions written consent is best practice. Verbal or implied consent should be recorded and evidenced. If consent is withheld this should be clearly recorded in writing.

Staff should also consider who will be attending such a meeting and whether the child/person is under the direct care of the professionals involved and that a need to know can be demonstrated.

Multi-Agency Sharing Practice

In situations where multi-agency groups meet to share practice and discussion about interventions with children/adults who may not be under their direct care, the name of the child/person and/or their family members must not be disclosed. All such discussions must be anonymised. There must be good professional reasons for sharing information and the information shared must be justified and relevant. The shared information must be in the best interests of the child and be able to be evidenced and recorded. This applies to both adults and children.

Appendix 4 –Sharing Information on Groups of Individuals

Bulk Data Transfers of Identifiable information

National initiatives such as Screening, Health Surveillance or Health Improvement programs can often be aided by sharing multiple identifiable records or parts of records held by one agency with a partner agency that has responsibility for delivering a programme.

In this case the agencies involved should agree how they will obtain appropriate consent to this type of information sharing. Best practice would indicate that all individuals whose identifiable information may require to be shared should be informed of the intent to share and the specific purpose for which the information will be used.

The agencies should agree whether explicit consent is to be sought from every individual or whether they will adopt an ‘opt out’ approach. The ‘opt out’ approach has deemed adequate in some circumstances to share information between different NHS organisations. This is where the individuals are informed of the intent to share and the purpose, but where the sharing will take place unless they explicitly register their wish for information not to be shared.

Bulk Data Transfers for planning, research or audit purposes

All information shared between partner agencies for use solely in service management, planning, research or audit purpose should be anonymised and all identifying information removed.

Appendix 5 - Criminal Justice Legislation

The Management of Offenders etc (Scotland) Act 2005, Section 1 places an obligation on key partners including local authorities, NHS Boards and the Police to cooperate in terms of this client group. Section 2 defines co-operation as ‘sharing information’ and defines what is meant by this. This would place legislative demands on the service to share information to protect both the individual and the public and health and other professionals. The Act also introduces Multi Agency Public Protection Arrangements (MAPPA’s) which require partners to share information in order to reduce re-offending and contribute to public safety.

The operational guidance for Criminal Justice professionals will reflect the general principals of the Information Sharing Protocol but will be proscribed by the legislative constraints and expectations placed on them by the Scottish executive.

Appendix 6 – Legislation & Reference Materials

Relevant Legislation

- Data Protection Act (1998)
- Data Protection (Subject Access Modification) (Health) Order 2000
- DATA Protection (Subject Access Modification) (Social Work) Order 2000
- Access to Health Records Act 1990 Sect 3 (1) (a)
- Crime & Disorder Act (1998)
- The Children (Scotland) Act 1995
- The Human Rights Act 1998
- Common Law Duty of Confidentiality
- Social Work (Scotland) 1968
- NHS (Scotland) Act 1978
- Freedom of Information (Scotland) Act 2002
- Adults with Incapacity (Scotland) Act 2000
- Mental Health (Care and Treatment)(Scotland) Act 2003
- Family Law (Scotland) Act 2006

Relevant Reference Documents

- The European Charter for Children in Hospital 1998
- The Legal aspects of Child Health Care (1996) (Bridget Dimond, Mosby London (Pages 52-65))
- The New Handbook of Children's Rights (2000) (Bob Franklin (ED) Routledge, London (Pages 200-208))
- NHS Scotland Security Policy
- NHS Borders IT Security Policy
- Individual professional codes of practice regarding record keeping
- Confidentiality Guidance from the General Medical Council
- Protecting & Using Patient Information – Manual for Caldicott Guardians [1999]
- 'Code of Practice for Protecting Patient Confidentiality' Final Report [2002]
- NHS Borders Records Management Policy [Currently being finalised]
- NHS Borders Completion of Health Records Policy [2005]
- Codes of Practice on the Adults with Incapacity (Scotland) Act 2000

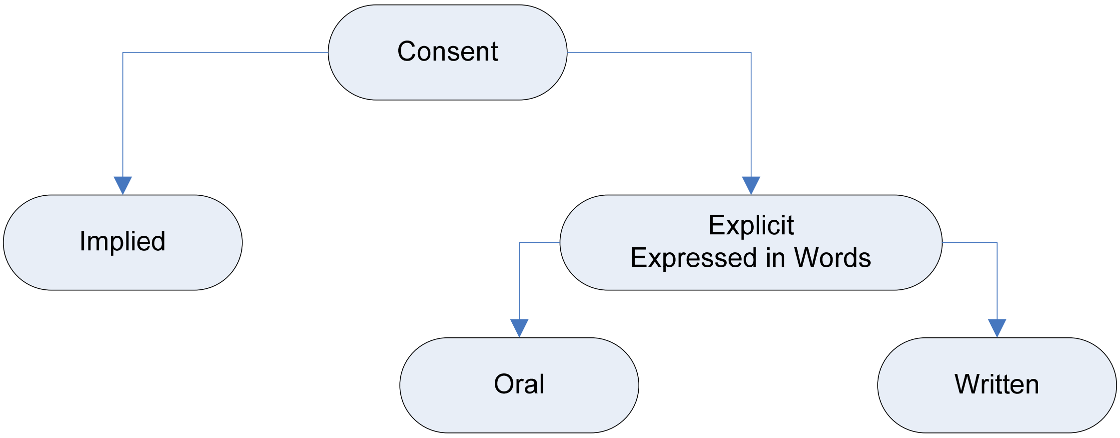
Appendix 7 – Definition of consent

Principles of consent –

- Fair explanation of the procedures/process to be followed and their purpose
- Description of any risks reasonably to be expected
- Description of any benefits reasonably to be expected
- Disclosure of any appropriate alternatives that might be advantageous to the client.

Types of Consent

- Consent is either implied or expressed
- Expressed can be sub divided into oral and written



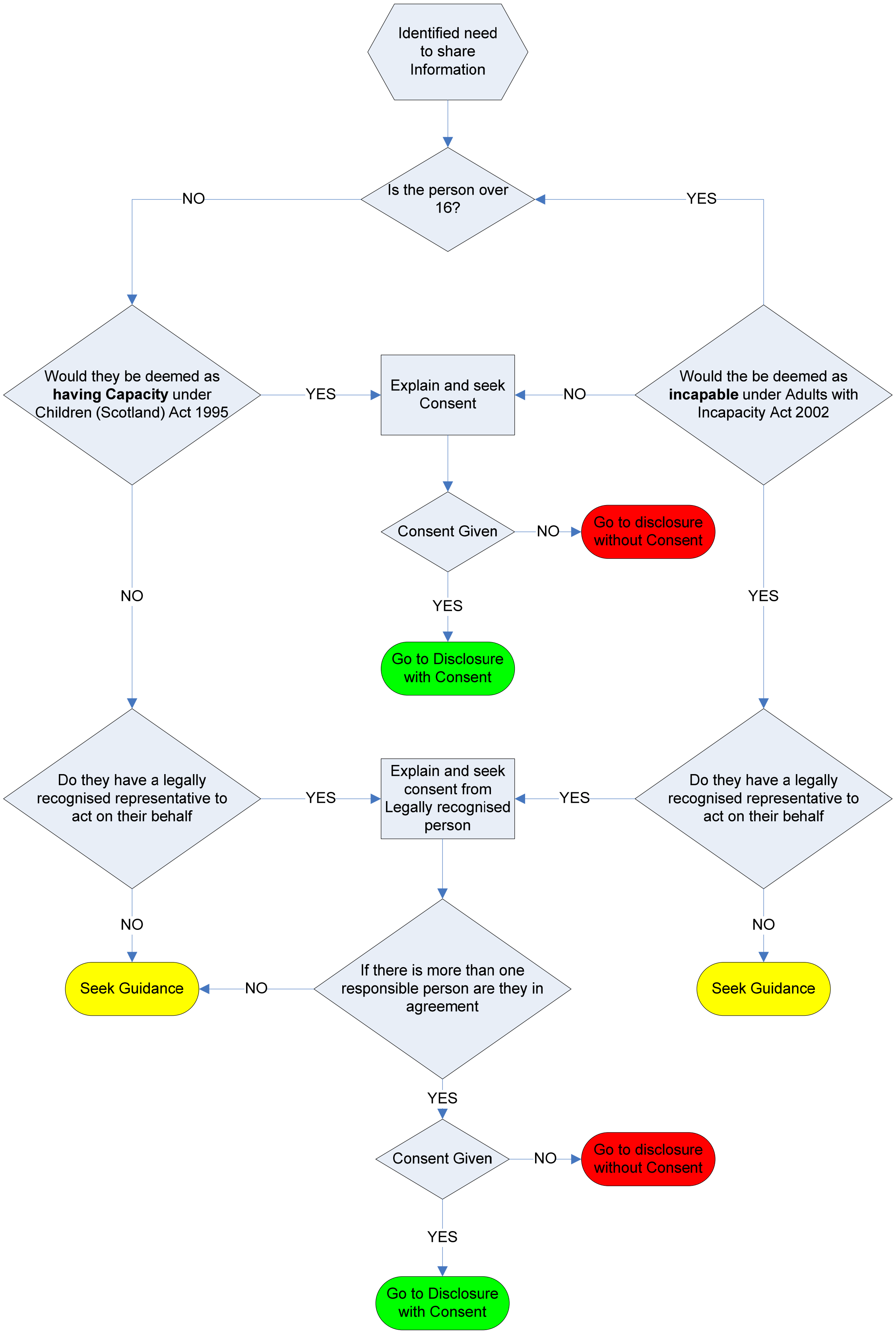
Implied Consent – where consent can be inferred from a relevant action E.g. the client /patient turns up for assessment / interview / presents for treatment

Expressed Consent – This can be written or oral consent.

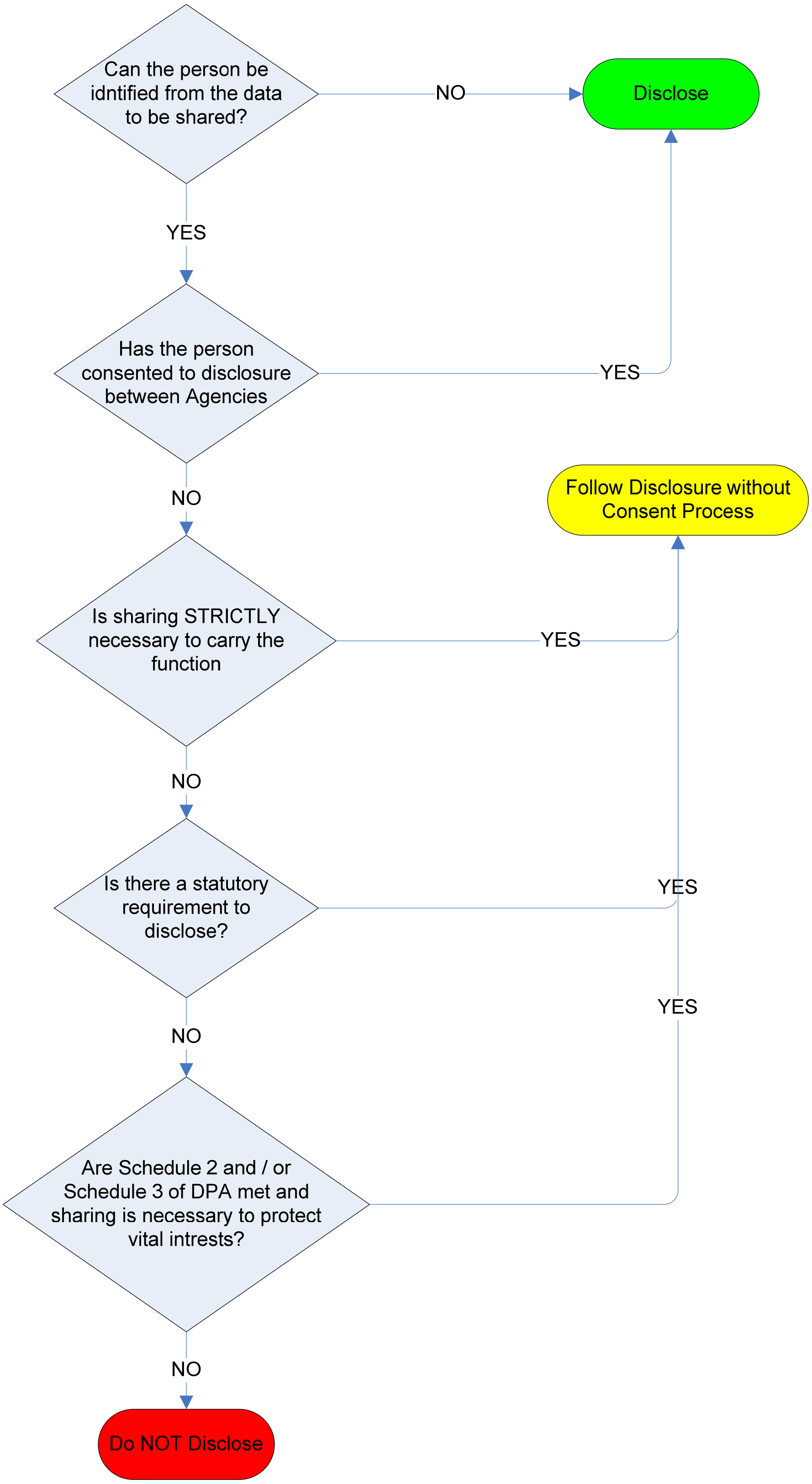
Written Consent - is better as it can be evidenced that consent was obtained. A proforma detailing the terms and conditions of consent can be used or a signature denoting consent can be obtained.

Oral Consent - can be given by the client which, where possible, is witnessed. Both witnessing parties would then sign a notation to this effect in the client's record.

Appendix 8 - Flowchart - Obtaining Consent



Appendix 9 - Flowchart - Decision to Disclose

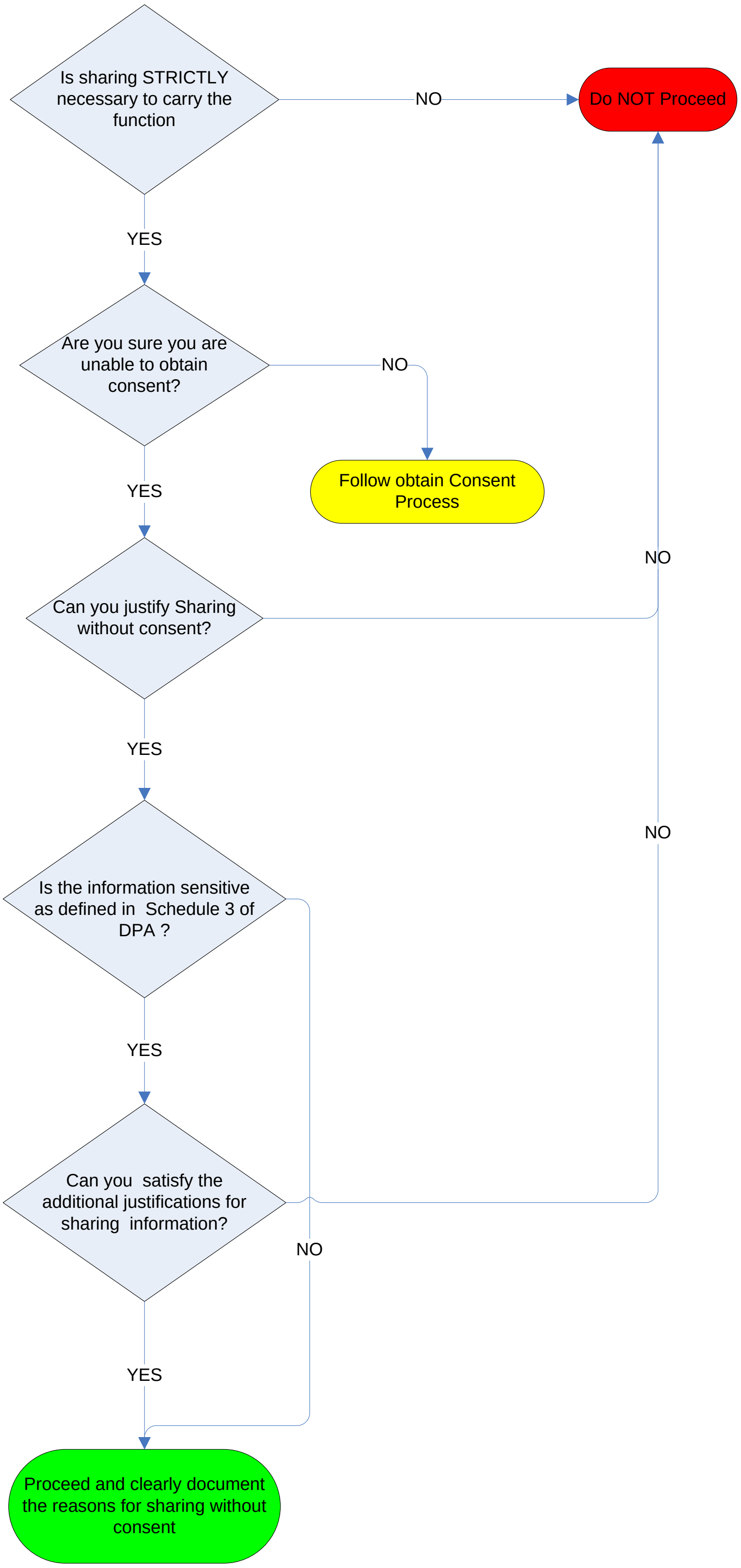


Adapted from eCARE Gold Standard Protocol for Information Sharing

Appendix 10 – Flowchart – Disclosure without Consent

Justifiable Reasons to share without Consent

To comply with a legal obligation
To protect vital interests of a service user and it is life/death
To provide information for legal purposes
To carry out a statutory, government or other function of a public nature



Additional Justifications to share without Consent

You are a health professional and are sharing for medical purposes
To protect vital interests of a service user or another persons and it is life/ death
To provide information for equal opportunities purposes
For research purposes which are substantially in the public interest

Adapted from eCARE Gold Standard Protocol for Information Sharing