



Department of
Health

An Roinn Sláinte

Mánnystrie O Poustie

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Code of Practice on Protecting the Confidentiality of Service User Information

April 2019

FOREWORD

All users of our health and social care services have the right to expect that any personal information they provide will be treated as confidential. However, the appropriate use and sharing of personal information forms an essential part of the provision of health and social care for the benefit of individual service users and the effective functioning of health and social services. Colleagues working within health and social services are well aware of their ethical and legal obligation to protect the information entrusted to them by users of the services.

The Code of Practice on confidentiality, provides support and guidance for all those involved in health and social care, concerning decisions about the protection, use and disclosure of service user information. The Code was developed by the Privacy Advisory Committee (PAC), following a comprehensive round of public consultation during 2011. Organisations consulted at that time included the Patient and Client Council, Professional Regulatory Bodies and the Information Commissioner's Office.

The Code has now been updated to take account of the General Data Protection Regulation (GDPR) and Data Protection Act 2018. A comprehensive review will be undertaken during the development of Regulations to give effect to the Health and Social Care (Control of Data Processing) Act (Northern Ireland) 2016.

The Code provides an invaluable reference point, on all matters related to privacy and confidentiality, for everyone working within health and social care in Northern Ireland.



A handwritten signature in blue ink, appearing to read 'R. H. H.', written on a white background.

Permanent Secretary
Department of Health
April 2019

Contents

Foreword

Preface

Executive Summary

1. Introduction
2. Service User Information
 - Keeping service users informed
 - Consent
 - Supporting the service user's right of access to their information
 - Respecting privacy in seeking and in using service user information
 - Maintaining information in a form which protects the identity of the service user
 - Maintaining the confidentiality of information after a service user's death
3. The purpose of any anticipated use or disclosure of person identifiable service user information
 - (A) The use and disclosure of person identifiable information for the direct care of that service user
 - Consent in the provision of direct care
 - Emergency situations
 - Review of care, including clinical audit
 - Multidisciplinary teams and inter-agency working
 - Informal carers
 - Dual roles
 - Summary
 - (B) The use and disclosure of person identifiable information for purposes of health and social care not directly related to care of that service user (secondary uses)
 - Anonymisation
 - Express consent
 - The need for a clear public interest
 - Opt-out
 - Information governance
 - Summary

(C) The use and disclosure of person identifiable information for other purposes

Consent and the use and disclosure of information for other purposes

Legal obligations to disclose

Discretionary disclosures in the public interest

Flow diagram to assist good practice

Summary

4. Decision-making about whether to use or disclose personal information relating to adults lacking capacity

Keeping service users informed and seeking consent

Information for direct care

Information for secondary uses

Disclosures in the public interest

Protection of vulnerable adults

Determining 'best interests'

Carers and advocates

Summary

5. Decision-making about whether to use or disclose personal information relating to children

Keeping children informed and seeking consent

Access to a child's health and social care record

Information for direct care

Information for secondary uses

Disclosures in the public interest

Protection of children

Summary

Appendix 1: The Principal Laws Relating to Confidentiality and Disclosure

Appendix 2: The Ethics of Confidentiality

Appendix 3: Membership of Privacy Advisory Committee (Northern Ireland)

Preface

This Code of Practice is principally concerned with identifiable service user information. Uses or disclosures of such information are only justified where:

- the service user has given his or her consent, or
- there is a statutory requirement to use or disclose the information, or
- the balance of public and private interests favours disclosure. In such situations there must be a substantial public interest favouring disclosure which outweighs both the private interests of the individual and the public interest in safeguarding confidentiality.

This Code of Practice was equality screened in accordance with section 75 of the Northern Ireland Act 1998 which requires the Department to “have due regard” to the need to promote equality of opportunity across nine categories and also to “have regard” to the desirability of promoting good relations across three categories. Equality screening is carried out to determine if a policy or practice is likely to have a significant impact on equality of opportunity and should therefore be subjected to an equality impact assessment (EQIA). The Department concluded that an EQIA was not required because the Code of Practice will affect all those accessing and working in health and social services. This is a positive initiative which will raise the profile of confidentiality, making staff more aware of the need to keep information confidential and supporting them in making sound decisions about when and how information can and should be shared and, at the same time, providing reassurance to service users and making them more aware of their rights in relation to their personal information. The Department will make this document available in alternative formats, such as Braille, large print and audio cassette, upon request.

In Northern Ireland there is no equivalent to section 251 of the National Health Service Act 2006, which allows the setting aside of the common law duty of confidentiality for essential health and social care purposes. The need for statutory provision for health and social care information governance, including the uses and disclosures of confidential identifiable service user information, remains under review by the Department.

The Privacy Advisory Committee (Northern Ireland) (Appendix 3) will support Personal Data Guardians and the Regional Quality Improvement Authority in ensuring that the information governance standards reflected by this Code of Practice are maintained by all organisations providing health and social care.

EXECUTIVE SUMMARY

Principles

The nature of the obligation to protect confidentiality can be expressed in terms of three core principles:

- individuals have a fundamental right to the confidentiality and privacy of information related to their health and social care;
- individuals have a right to control access to and disclosure of their own health and social care information by giving, withholding or withdrawing consent;
- when considering whether to disclose confidential information, health and social care staff should have regard to whether the disclosure is necessary, proportionate and accompanied by any undue risks.

Particular care is needed on the part of health and social care staff to ensure that the right to privacy of vulnerable people – specifically adults with incapacity and children – is respected and that the duty of confidentiality owed to them is fulfilled.

Service User Information

Service users must be kept informed in an accessible manner about the uses and disclosures of their information. It is important that service users are informed of the limitations of confidentiality.

Service users should also be informed of the circumstances in which they can give, withhold or withdraw consent to the use of their information.

Service users should be given an opportunity to discuss any concerns they may have about possible uses of their information.

If a service user refuses to consent to disclosure of personal information, the information cannot be disclosed, unless, exceptionally, a justification other than consent exists.

In general, service users have a right of access to their health and social care records and to any other information held on them by health and social care organisations.

Information in the record about third parties (other than relevant health professionals) should not in general be disclosed without the consent of the third party.

Service users should not be asked questions which may require them to reveal private, sensitive or confidential information in a way which will be overheard or inadvertently accessible to others.

Staff should reasonably satisfy themselves that personal service user information will be kept in a manner which is in keeping with high standards of security.

The confidential nature of a service user's information and the ethical obligation on health and social care staff to respect that confidentiality continue to apply after the death of that service user. Where a competent service user has made an explicit request before his or her death that the confidence be maintained, then the service user's request should normally be respected.

The purpose of any anticipated use or disclosure of person identifiable service user information

(A) The use and disclosure of personal identifiable information for the direct care of that service user

Service users must be informed in a manner appropriate to their communication needs of what information sharing is necessary for their care and the likely extent of the sharing for a particular episode of care.

In emergency situations uses or disclosures may be made, but only the minimum necessary information should be used or disclosed to deal with the emergency situation.

Review of care carried out by members of the care team and those supporting them have sufficient connection with that direct care for the sharing of information to be justified on the basis of implied consent, provided the individual has been informed.

Where it is planned to involve staff from other agencies this should first be discussed with the service user and their explicit consent sought.

When other agencies request information about service users, health and social care staff should seek the consent of the service user.

In situations of on-going need for care and support, the potential benefits of information sharing with their informal carers should be discussed with the service user.

The confidentiality of informal carers should be respected and information about them should not normally be disclosed without their consent.

Where a staff member has dual responsibilities it is important that they explain to the service user at the start of any consultation or assessment in what capacity they are seeing them and the purpose of the consultation or assessment.

(B)The use and disclosure of personal identifiable information for purposes of health and social care not directly related to care of that service user (secondary uses)

All organisations seeking service user information for other than direct care should be seeking anonymised or pseudonymised data.

Also when the proposed use or disclosure of identifiable information relates to health and social care, but is not directly for the care of that service user, the common law requires that the express consent of that service user should normally be obtained.

The possible exceptions to requirement for consent are where a statute, court or tribunal imposes a requirement to disclose or there is an overriding public interest in the use or disclosure.

Organisations should not use personal identifiable information for secondary uses if the service user in question has opted out by specifically refusing consent.

(C)The use and disclosure of personal identifiable information for other purposes

Consent is not required where there is a statutory obligation to disclose or a discretionary disclosure is justified in the public interest.

Where a statute, court or tribunal imposes a requirement to disclose information, care should be taken only to disclose the information required to comply with and fulfil the purpose of the law.

In all cases of discretionary disclosure in the public interest the test is whether the release of information to protect the interests of a third party exceptionally prevails both over the duty of confidence owed to the service user and the public interest in a confidential health and social care service.

Decision-making about the personal information of adults lacking capacity

If an adult with impaired capacity is able to take part in decision-making then they should be provided with an explanation of why it is proposed to use or disclose information and their consent sought, including consent to talk to others involved in their care or treatment.

Where an adult lacks capacity decisions should in general be made in their best interests.

For Direct Care personal information should not be shared more widely than is strictly necessary.

For all proposed Secondary Uses the same principles apply as for capacitous adults. Where an adult lacks capacity to consent, decisions should in general be made in their best interests.

Information required by statute, court order or a tribunal must be disclosed.

Information should be disclosed if it is necessary to protect an adult who lacks capacity, or someone else, from risk of death or serious harm.

Protection of Vulnerable Adults. Confidentiality is important and information sharing should be proportionate to the risk of harm. Some limited information may need to be shared, with consent if possible, in order to decide if there is a risk that would justify further disclosures.

Decision-making about the personal information of children

Children have the same rights to privacy as all other persons and there is the same duty of confidentiality to them as there is to adults.

If a child is able to take part in decision-making then they should be provided with an explanation of why it is proposed to use or disclose information.

A child's consent should normally be sought, including consent to talk to parents and others involved in their care or treatment.

Where a child is not competent to consent, the consent of a parent or person with parental responsibility should be sought.

For all proposed Secondary Uses the same principles apply as for adults. Where a child lacks capacity to consent, the consent of a parent or appropriate authority should be sought.

Information required by statute, court order or a tribunal must be disclosed.

Information should be disclosed if it is necessary to protect a child, or someone else, from risk of death or serious harm.

Child protection

Health and social care staff play a crucial role in protecting children from abuse and neglect. Staff may be told or notice things that others may not and may have access to confidential information that causes them to have concern for the safety or well-being of children. The assessed levels of actual or potential harm to a child, as well as the substance and imminence of such harm, should inform decision-making with regard to the sharing of personal identifiable information. The welfare of the child is paramount. Where there is concern that a child or young person is at risk of abuse or neglect, staff should make a referral to the Child Protection/Gateway Service¹ (which will determine whether any further action is required) unless the increased risk to the safety or welfare of the child is deemed to clearly outweigh the benefits of sharing information through such a referral. Where a child is considered to be at immediate risk of serious harm, this information should be reported to the police. If a child or young person with capacity objects to information being disclosed, staff should consider the child's or young person's reasons and carefully weigh the possible consequences of not sharing the information against the harm that sharing the information might cause

CHAPTER 1. Introduction

- 1.1 The use and sharing of personal information about service users forms an essential part of the provision of health and social care, benefiting individual service users, often necessary for the effective functioning of health and social services and often necessary in the public interest. The essential nature of such uses, however, needs to be set alongside the expectations service users have that all personal information will be kept confidential. All health and social care staff have strong legal and ethical obligations to protect service user information (Appendices 1 and 2).
- 1.2 The relationship between health and social care staff and a service user should be one of fidelity or trust. Service users have a tacit understanding that private information will not be used or disclosed without their awareness and consent. Service users have a legal right to confidentiality and all staff have a duty of confidence.
- 1.3 The nature of the obligation to protect confidentiality can be expressed in terms of three core principles:
 - individuals have a fundamental right to the confidentiality and privacy of information related to their health and social care;
 - individuals have a right to control access to, and disclosure of, their own health and social care information by giving, withholding or withdrawing consent;
 - for any proposed disclosure of confidential information, health and social care staff should have regard to whether the disclosure is necessary, proportionate and accompanied by any undue risks.
- 1.4 Each service user's right to privacy and member of staff's duty of confidentiality exist regardless of the form in which information is held or communicated. They apply to electronic records, paper records, photographs, videos and biological samples; it also does not matter whether the information is held in the service user's own record or in someone else's record.
- 1.5 Particular care is needed on the part of health and social care staff to ensure that the right to privacy of vulnerable people – specifically adults with incapacity and children – is respected and that the duty of confidentiality owed to them is fulfilled.

- 1.6 The aim of this revised Code of Practice is to support staff in making good decisions about the protection, use and disclosure of service user information. It provides practical guidance to assist decision-making with respect to service user information.
- 1.7 The Code of Practice should be the reference point for all staff and any questions which it does not answer should be addressed to the relevant Personal Data Guardian or member of staff responsible for data protection. A code of practice cannot address all situations in detail and there will always be difficult judgements to be made. Data protection law, human rights law and the common law of confidentiality are all complex and can interact in complicated ways in particular situations. The Code should not be taken as a complete statement of the law and legal advice should be sought when necessary. Information about the relevant ethical and legal standards applying in Northern Ireland is summarised in Appendices 1 and 2.
- 1.8 This revised Code of Practice replaces the earlier guidance issued in 2009. Where relevant it refers to the [Data Sharing Code of Practice of the Information Commissioner's Office \(2011\)](#). Further legal and ethical developments, changes in policy, or relevant new guidance may occur after this Code of Practice has been issued. Health and social care staff should endeavour to keep themselves informed of any developments which may be relevant to their practice.
- 1.9 Issues in relation to the consent principle and to the way service user information should be stored and handled are considered in Chapter 2. In Chapter 3 the duty of confidentiality is considered in relation to three different situations, depending on the purpose behind the proposed use or disclosure, namely (A) the use and disclosure of information for the direct care of that service user; (B) the use and disclosure of information for purposes of health and social care not directly related to the care of that service user (secondary uses); and (C) the use and disclosure of information for other purposes. Particular consideration is then given to good practice in making decisions about information relating to adults lacking capacity (Chapter 4) and to children (Chapter 5).
- 1.10 New issues in relation to confidentiality and privacy are constantly arising. This Code of Practice must of necessity be a living document and will therefore undergo regular review and updating.

CHAPTER 2. Service User Information

2.1 Health and social care professionals have an obligation to keep records. This should be made clear to service users and any concerns they have about records should be addressed.

Keeping service users informed

2.2 Modern health and social care services often involve sharing information between staff to provide optimal care and treatment, but the extent of and their control over such sharing is not always known to service users. Service users must be kept informed in an accessible manner (including making use of appropriate communication supports) about the uses and disclosures of their information. It is important that service users are informed of the limitations of confidentiality both in terms of any relevant statutory obligations to disclose confidential information and of the duty of health and social care staff to disclose information in the public interest (see 3.25 – 3.34).

2.3 Service users should also be informed of the circumstances in which they can give, withhold or withdraw consent to the use of their information.

2.4 In general, service users should be informed of:

- what kinds of information are being recorded and retained;
- the purposes for which the information is being recorded and retained;
- what protections are in place to ensure non-disclosure of their information;
- what kinds of information sharing will usually occur, with whom and for what purpose;
- the choices available to them about how their information may be used and disclosed;
- their rights to access and where necessary to correct the information held about them within health and/or social care records.

2.5 Readily accessible leaflets, for example as enclosures in new appointment letters, is one way of keeping service users informed. Service users should be given an opportunity to discuss any concerns they may have about possible uses of their information. It should be made clear to service users that they may object to specific secondary uses of their personal information (see 3.14).

Consent

- 2.6 Consent is the means by which service users can exercise control over the dissemination of their confidential information. Use or disclosure of person identifiable information is normally justified by the consent of the service user. For most uses of information, consent may be withdrawn.
- 2.7 If the service user refuses to consent to disclosure of personal information, the information cannot be disclosed, unless, exceptionally, a justification other than consent exists. Staff should discuss with the service user why disclosure may be in the service user's best interests and the potential disadvantages that may arise. Unless there is an overriding public interest justification, information should not be disclosed on a "best interests" basis where an adult with capacity refuses to consent to disclosure.
- 2.8 Disclosure in a service user's best interests would usually be justified:
- where an adult is incapable of giving or withholding consent and you believe they are a victim of neglect or of emotional or physical abuse, or at risk of suicide;
 - where without disclosure you would not be acting in the overall best interests of a child, who does not have the understanding to make the decision, and where it is impracticable or inappropriate to obtain consent from the person with parental responsibility.
- 2.9 Where a service user refuses to consent to a specific disclosure, withdraws consent or is incapable of giving consent, this should be documented in their record.

Supporting the service user's right of access to their information

- 2.10 In general service users have a right of access to their health and social care records and to any other information held on them by health and social care organisations.
- 2.11 However, the law allows for records and other information not to be disclosed if the disclosure may cause serious harm to the physical or mental health of the service user or of any other person.
- 2.12 Information in the record about third parties (other than relevant health professionals) should not in general be disclosed without the consent of the third party (see the Information Commissioner's Guidance [Right of Access Requests](#))

Respecting privacy in seeking and in using service user information

- 2.13 A lack of respect for the privacy of service users may be shown not only in how information is used or disclosed, but also in the manner in which it is initially obtained. Service users should not be asked questions which may require them to reveal private, sensitive or confidential information in a way which will be overheard or inadvertently accessible to others. Respect for privacy requires a reasonable caution in soliciting the information necessary for the care of service users. Service users must not be deceived or misled as to the purpose or purposes for which their information is sought.
- 2.14 Private information should in general only be requested from or provided to service users in an appropriate environment, for example, where others cannot overhear. What exactly is appropriate will depend on the nature of the information likely to be offered by/ to the service user. Reasonable steps should be taken to ensure the privacy of the service user in a proportionate manner. Any means of communication of private information (for example, telephone or email) should ensure the privacy of the service user.
- 2.15 If a member of staff is seeking information from another member of staff, then it should only be sought from someone with legitimate access to that information and with the authority to disclose it. The identity of any person requesting information, including someone claiming to be a member of health and social care staff, should be checked when necessary.
- 2.16 Gossiping is clearly an improper use of confidential service user information, but care must also be taken when discussing cases in public places. Cases may need to be discussed with colleagues (for example, to gain advice or share experience) but the service user should not be identified unnecessarily and care must be taken that others do not overhear these conversations.

Maintaining information in a form which protects the identity of the service user

- 2.17 High standards of security should apply to service user information. Staff should reasonably satisfy themselves that personal service user information will be kept in a manner which is in keeping with such standards. This includes authoritative and comprehensive information governance, access controls, the routine auditing of access requests and audit trails.
- 2.18 Good records management standards and practices underpin respect for the privacy of service user information. Specifically, it is essential that case files and associated records (such as images or notes) are stored securely, that they can be located at any time and that they are disposed of in a way and at a time consistent with the regional guidelines and the organisation's disposal schedule.
- 2.19 Using an electronic record can provide greater quality and security of health and social care information than the traditional forms of documentation. However, they also have the potential to make a service user's information more readily available to a wider range of people. Electronic records therefore must be appropriately protected (for example the use of passwords with role-based access controls). Specific consideration needs to be given to the governance, security and access arrangements for pooled records and pooled information. Similarly the transmission of service user information using electronic methods of communication including the intranet and internet must be appropriately protected.
- 2.20 Many proposed uses of service user information do not need to identify service users. In such situations the information should be held in the form which minimizes any risk of identification. Anonymisation and pseudonymisation are key means for protecting the rights of service users. Where appropriate all organisations should aim to anonymise or pseudonymise information.
- 2.21 It is common to refer to information as 'anonymised' when it is not immediately apparent to whom the information refers. However, for the purposes of data protection, a much stricter definition of 'anonymous' is provided by law. For personal data to have been rendered anonymous it must no longer be possible for anyone to identify the person who is the

subject of the data directly (that is, from the data itself) or indirectly (that is, from the data itself in conjunction with other data or means that are 'reasonably likely to be used', such as an identification number or one or more factors specific to the subject's physical, physiological, mental, economic, cultural or social identity).

- 2.22 'Pseudonymised information' is like anonymised information in that when it is in the possession of the holder it cannot be used by the holder to identify an individual. However it differs in that the original provider of the information, who may even belong to the same organisation, may retain a means of identifying individuals. This will often be achieved by attaching codes or other unique references to information so that the data will only be identifiable to those who have access to the key or index. Pseudonymisation allows information about the same individual to be linked in a way that true anonymisation does not.
- 2.23 Where full anonymisation is impracticable, the information holder will need to consider the potential risks to service user confidentiality before sharing the information in a pseudonymised form, so as to ensure that personal identifiable information is not inappropriately disclosed.

Maintaining the confidentiality of information after a service user's death

- 2.24 The confidential nature of a service user's information and the ethical obligation on health and social care staff to respect that confidentiality continue to apply after the death of that service user. However, just as in life, the duty to maintain confidentiality after death is not absolute, but is subject to ethical and legal limitations. Even though the service user can no longer be harmed, there is still a public interest in the maintenance of confidentiality after death. Disclosure of information after the death of a service user might also be an infringement of the right to private life of people associated with the service user.
- 2.25 Before he or she dies a competent service user (see 4.2) can give or withhold consent to disclosure after their death and such wishes should be respected. In particular, where a competent service user has made an explicit request before his or her death that their confidence be maintained, then the service user's request should normally be respected. In relation to Freedom of Information Act requests the Information Commissioner advises that, where a duty of confidence arises exemption from such a request will continue to apply after the

death of the person concerned (see the Information Commissioner's [Information about the deceased](#)).

SUMMARY

1. Service users must be kept informed in an accessible manner about the uses and disclosures of their information. It is important that service users are informed of the limitations of confidentiality.
2. Service users should also be informed of the circumstances in which they can give, withhold or withdraw consent to the use of their information.
3. Service users should be given an opportunity to discuss any concerns they may have about possible uses of their information.
4. If a service user refuses to consent to disclosure of personal information, the information cannot be disclosed, unless, exceptionally, a justification other than consent exists.
5. In general service users have a right of access to their health and social care records and to any other information held on them by health and social care organisations.
6. Information in the record about third parties (other than relevant health professionals) should not in general be disclosed without the consent of the third party.
7. Service users should not be asked questions which may require them to reveal private, sensitive or confidential information in a way which will be overheard or inadvertently accessible to others.
8. Staff should reasonably satisfy themselves that personal service user information will be kept in a manner which is in keeping with high standards of security.
9. The confidential nature of a service user's information and the ethical obligation on health and social care staff to respect that confidentiality continue to apply after the death of that service user. Where a competent service user has made an explicit request before his or her death that their confidence be maintained, then the service user's request should normally be respected.

CHAPTER 3. The purpose of any anticipated use or disclosure of person identifiable service user information

- 3.1 A key means of protecting service user information is the requirement for a clear and unambiguous purpose for any contemplated use or disclosure. Clarity about the purpose of any contemplated use or disclosure is a key feature of ethics, human rights law, data protection law and the common law of confidentiality. Only the minimum information consistent with that purpose should be used or disclosed.
- 3.2 The particular purpose of any contemplated use or disclosure of service user information will be one of the following:
- (A) use and disclosure of personal identifiable information for the *direct care* of that service user;
 - (B) use and disclosure of personal identifiable information for purposes of health and social care *not directly related to the care of that service user* (secondary uses);
 - (C) uses and disclosures of personal identifiable information for purposes other than A or B.

It is important to note that a use or disclosure for any of these purposes may have several possible justifications. In particular, instances of use or disclosure might be justified on the basis of the consent of the service user, a statutory obligation or the overriding public interest.

- 3.3 To facilitate good practice a flow diagram of the decision-making process involved when considering whether to disclose information is provided at the end of this chapter. This draws attention to the most relevant points to bear in mind for each of the purposes in question.

(A) The use and disclosure of personal identifiable information for the direct care of that service user

Consent in the provision of direct care

- 3.4 As with any other intervention forming part of the provision of direct care for a service user, the service user's consent occupies a pivotal role in legitimising the uses and disclosures of their information. Service users must be informed in a manner appropriate to their communication needs of what information sharing is necessary for their care and the likely extent of the sharing for a particular episode of care. In addition to the multidisciplinary nature of modern health and social care they should be

informed about the necessary involvement of a range of administrative staff (eg: secretarial, clerical, audit-assistant staff) who support professional staff. Provided service users are adequately informed in this way (see also paras 2.2-2.5 above), express consent is not necessary and their consent to the disclosure of information necessary for their care may be inferred from their acceptance of that care (implied consent; see also paras 2.6-2.9 above).

Emergency situations

- 3.5 In emergency situations it may not be possible to keep a service user properly informed and to gain their consent for the sharing of their information for their care. In such situations, uses or disclosures may be made, but only the minimum necessary information should be used or disclosed to deal with the emergency situation. Reasonable care should be taken not to override any relevant legally binding wishes of the service user which have been expressed in advance of the situation arising. As soon as possible after disclosure, the service user should be told what information has been disclosed and their consent sought for any necessary further disclosures.

Review of care

- 3.6 Review of care, including clinical audit and case review carried out by members of the care team and those supporting them, is for the purpose of improving the direct care of that service user. Such purposes have sufficient connection with that direct care for the sharing of information during the review of care to be justified on the basis of implied consent, provided the individual has been informed.

Multidisciplinary teams and inter-agency working

- 3.7 **Multidisciplinary teams.** When health and social care staff legitimately disclose service user information for the care of that person in a multidisciplinary team, such disclosure should take place on a clear basis of agreed policies and procedures for information sharing. Personal information should not be shared more widely than is strictly necessary.
- 3.8 **Interagency working.** It is common practice in many areas of health and social care provision to involve outside agencies in providing services. This inevitably involves discussions about service users at various points in their care. Issues about sharing information may arise

in the context of verbal or written reports, or attendance at case conferences. Any proposed disclosure should take place on a clear basis of agreed policies or protocols for information sharing.

- 3.9 Where it is planned to involve staff from other agencies this should first be discussed with the service user and their explicit consent sought. The particular purpose of involving the other agency should be clarified along with the purpose of the proposed information sharing. When other agencies request information about service users, health and social care staff should seek the consent of the service user. In all instances of inter-agency working, personal information should not be shared more widely than is strictly necessary.

Informal carers

- 3.10 **Sharing information about service users with informal carers.** Family members and other persons who are providing informal care for a service user have an understandable need for information about the service user's care needs and their management. Such knowledge may benefit both the service user and the carer by, for example, creating a better understanding of the needs of the service user and promoting more appropriate responses to them. However, the fact that such information sharing may be beneficial does not diminish the duty of confidentiality owed to the service user. In situations of ongoing need for care and support, the potential benefits of sharing information with their informal carers should therefore be discussed with the service user.
- 3.11 **Sharing information about service users provided by informal carers.** In general, the potential benefits of sharing information, obtained from an informal carer, with the service user should first be discussed with that informal carer. Difficulties may arise where the information might identify the carer, who does not wish the service user to identify the carer as the source. The decision on whether or not to share the information in such situations will therefore require a consideration of the risks and benefits to both the service user and the informal carer. This, in turn, may need to be explained to the informal carer in advance of any information sharing.
- 3.12 The confidentiality of informal carers should be respected. Information about them, irrespective of the source, should not normally be disclosed without their consent.

Dual roles

3.13 Wherever possible, health and social care staff should avoid situations where they have dual responsibilities and obligations to the same service user. This may arise, for example where a doctor finds him- or herself being a person's General Practitioner or Occupational Health Physician as well as that person's employer. Where a staff member has dual responsibilities it is important that they explain to the service user at the start of any consultation or assessment in what capacity they are seeing them and the purpose of the consultation or assessment. It should also be made clear to the service user the extent to which information given will not be treated as confidential. Nevertheless the general and professional obligations to maintain confidentiality remain.

(B) The use and disclosure of personal identifiable information for purposes of health and social care not directly related to care of that service user (secondary uses)

3.14 Some uses and disclosures of service user information are for purposes of health and social care not directly related to the care of an individual service user. Many uses of service user information are increasingly required for evidence-based practice and for a rational approach to health and social care service provision. The following are examples of such secondary uses: planning; financial management; commissioning of services; investigating complaints; auditing accounts; teaching; health and social care research; public health monitoring; registries; infectious disease reporting.

Anonymisation

3.15 Anonymised or pseudonymised information will usually be sufficient for purposes other than the direct care. Whether or not it is possible to obtain express consent personal information should be anonymised. All organisations seeking service user information for other than direct care should be seeking anonymised or pseudonymised data. The Health and Care Number (HCN) of service users should be used instead of usual patient identifiers such as name and address. However to achieve anonymisation some further step such as encryption needs to be taken.

Express consent

- 3.16 While the informed co-operation of a service user can provide a basis for inferring their consent to the use and disclosure of information required for their care (see paras 2.6 to 2.9 above), there is no behaviour which clearly implies consent to other uses and disclosures. Therefore when the proposed use or disclosure of identifiable information relates to health and social care, but is not directly for the care of that service user, the common law requires that the express consent of that service user should normally be obtained.
- 3.17 Where identifiable information is required and an organisation has a direct relationship with a service user it should be aiming to implement procedures for obtaining the express consent of the service user.
- 3.18 For all proposed research uses of personal identifiable information the express consent of the service user should normally be sought. Where consent is being sought this should be by health and social care staff who have a direct relationship with the individual service user.

The need for a clear public interest

- 3.19 If personal identifiable information is to be made available for secondary purposes, there must also be some clear public interest in making the information available, such as a clear benefit to service users or a clear general good (e.g. public safety). The possible exceptions to requirement for consent are where a statute, court or tribunal imposes a requirement to disclose or there is an overriding public interest in the use or disclosure (see paras 3.25 – 3.34 below).
- 3.20 All organisations seeking to use personal identifiable information should provide information to service users describing the information they want to use, why they need it and the choices they have.
- 3.21 Situations arise where the consent of service users cannot practicably be obtained for use or disclosure, yet there are clearly public health and social care interests at stake. Examples include disease registries for secondary uses, administrative and financial monitoring, and financial inspections - including probity checking to provide assurance on the level of service provision. Wherever possible the Honest Broker service should be used, for example for data linkage. The Health and Social Care (Control of Data Processing) Act (NI) 2016 will, once regulations have

been developed provide a legal basis for setting aside the common law duty of confidentiality (see Appendix 1).

Opt-out

- 3.22 Organisations should not use personal identifiable information for secondary uses if the service user in question has opted out by specifically refusing consent.

Information Governance

- 3.23 For all proposed secondary uses or disclosures information must be held under high standards of security.
- 3.24 On issues relating to Data Sharing Agreements and associated information governance provisions please refer to the Information Commissioner's *Data Sharing Code of Practice*, Sections 8 and 14.

(C) The use and disclosure of personal identifiable information for other purposes

- 3.25 It is sometimes both legally and ethically acceptable to use or disclose service user information for purposes which are neither for the direct care of that service user nor for a secondary health and social care purpose. Examples include: prevention of serious harm to third parties (such as injury, sexually transmitted disease, serious genetic risk); child protection; protecting vulnerable adults; prevention of terrorism; prevention, detection or prosecution of a serious crime; misuse of controlled drugs; investigation of serious professional misconduct.

Consent and the use and disclosure of information for other purposes

- 3.26 Consent is not required where there is a statutory obligation to disclose or a discretionary disclosure is justified in the public interest. However, it may be necessary to seek consent for a disclosure where the public interest served does not clearly override the public interest in maintaining confidentiality. In other circumstances it might still be appropriate to discuss disclosure with the service user in order to protect the relationship with them, even though the disclosure does not need their consent to be justified.

Legal obligations to disclose

- 3.27 Where a statute, court or tribunal imposes a requirement to disclose information, care should be taken only to disclose the information required to comply with and fulfil the purpose of the law (see Appendix 1). If there is a reason to believe that complying with a statutory obligation to disclose information would cause serious harm to the service user or another person, legal advice should be sought.
- 3.28 If appropriate, make sure that the service user is informed of the purpose of any proposed disclosure, to whom their information will be disclosed, and what information exactly is being disclosed.

Discretionary disclosures in the public interest

- 3.29 In all cases of discretionary disclosure in the public interest there is no legal obligation to disclose, rather whether or not disclosure can be justified depends on balancing the interests that are in conflict in each case; for example protecting a third party from serious harm. It needs to be borne in mind that every disclosure is an interference with the service user's right to privacy, while the benefits of disclosure will often be less certain. While a balancing of the service user's right to privacy against other rights and interests is always difficult, it is usually more easily performed where the conflict is with rights of identifiable third parties, such as in child protection, than where there is a conflict with a more diffuse public interest such as national security or public health. It is not sufficient that such disclosure might serve the protection of such an overriding public interest; rather the test is one of strict necessity in the specific circumstances of each case.
- 3.30 In situations involving disclosure to protect overriding rights of third parties, each case must be considered on its merits. The test is whether the release of information to protect the interests of a third party exceptionally prevails over the duty of confidence owed to the service user and the public interest in a confidential health and social care service. In performing the balancing exercise it is important to remember that there is a substantial public interest in the maintenance of confidentiality in health and social care services and not to construe the balance as being between the rights of an individual alone against the public interest.

3.31 Factors to consider when exercising a discretion to disclose in the public interest are:

- The nature and extent of the proposed disclosure.
- The importance of the interest that is at risk without disclosure, for example disclosure might be more easily justified where the life or integrity (physical or psychological) of a third party is at risk.
- The likelihood of the harm occurring in the individual case, that is, disclosure might be justified where there is a high likelihood of harm to the life of another, but not necessarily justified where there is a low likelihood of harm.
- The imminence of the harm, that is, disclosure might be justified where protection of the third party requires immediate action, but not where there is no more than a possibility that at some future point the service user might pose a threat to another.
- The existence of an appropriate person to whom disclosure can be considered.
- The necessity of the disclosure to avert the harm, that is, where there is no reasonable possibility of averting the harm without disclosure.
- The likelihood that disclosure can avert the harm, which requires that the health or social care staff member be satisfied that the harm to the third party or to the public interest is sufficiently likely to be averted by disclosure.

3.32 In all instances where judgment is involved, health and social care staff are urged to discuss the case with colleagues without revealing identifiable details of the service user and, if necessary, to seek legal or other specialist advice. It may be more appropriate in certain situations for the decision to be made by a middle or senior manager.

3.33 When a decision has been reached that disclosure is justified in a particular situation, there are requirements for how that disclosure should best be made. Most situations where decisions to disclose are reached require good communication with and support for service users whose confidentiality is to be breached. The member of staff should record in the health record or social care record details of all conversations, meetings and appointments involved in the decision to disclose or not to disclose.

3.34 Once a decision to disclose has been reached the usual procedure would be as follows:

- An explanation of the reasons for sharing information should be given in writing to the service user and/or people with responsibility for them such as parents
- The responsible member of staff should encourage the service user (and/or where appropriate, their legal representative) to inform the relevant authority (for example, police or social services). If the service user or legal representative agrees, the member of staff will require confirmation from the authority that such disclosure has been made.
- If the service user or their legal representative refuses to act, the responsible member of staff should then tell them that he or she intends to disclose the information to the relevant authority or person. He or she should then inform the authority, disclosing only relevant information and make available to the service user and/or their legal representative the information that he or she has released.
- Health and social care staff who decide to disclose confidential information (whether or not the service user or their legal representative has been informed beforehand) should be prepared to explain and justify their decision to the authority if called upon to do so.
- Ensure that the information disclosed will then be held in accordance with high standards of security.

Exceptions to this normal procedure could be where informing the subject in advance would prevent achieving the justified aim of the disclosure and where doing so would put the safety of the member of staff or another person at risk.

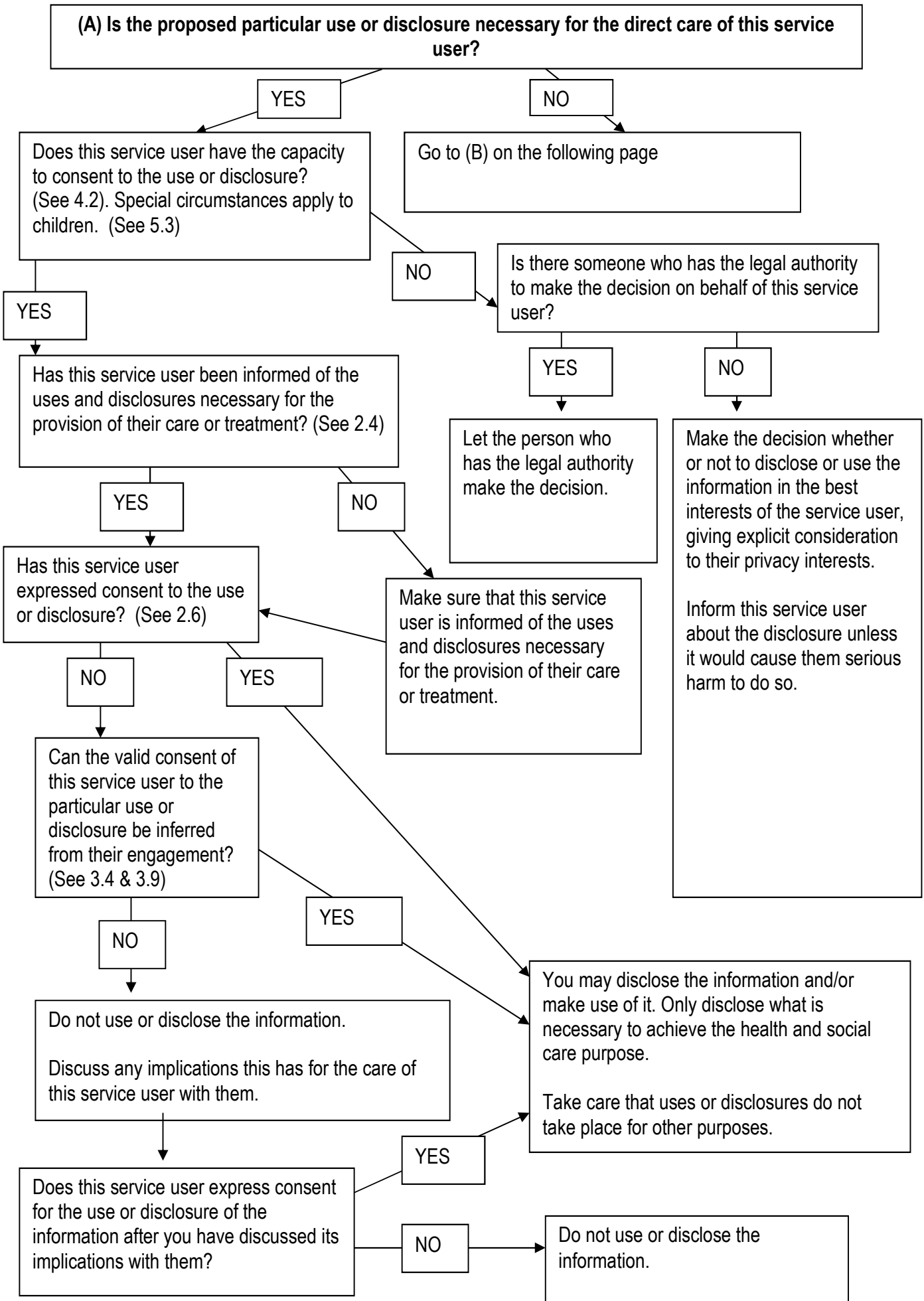
Flow diagram to assist good practice

3.35 The following flow chart provides a simple tool to direct attention to the key considerations in making good decisions about the use and disclosure of personal identifiable service user information. It should be used in conjunction with the text of this Code of Practice. It contains references, in brackets, to the particularly relevant paragraphs.

3.36 The chart falls into three sections which correspond to the distinction in the text between the three kinds of purpose of any proposed use or disclosure. These three kinds of purposes are:

- (A) use and disclosure of personal identifiable information for the direct care of that service user;
- (B) use and disclosure of personal identifiable information for purposes of health and social care not directly related to care of that service user;
- (C) use and disclosure of personal identifiable information for other purposes.

3.37 Any proposed use or disclosure will necessarily fall under one of these three general types of purpose. To use the decision tree begin by considering A and, where appropriate, proceed to B and then to C as indicated on the decision tree.



(B) Is the proposed use or disclosure for a health or social care purpose but not directly related to the care of this service user?

YES

NO

Is there a statutory obligation to use or disclose? (See 3.19)

Go to (C) on the following page.

NO

YES

Has this service user's consent been sought and their express consent given for the use or disclosure? (See 3.16)

Proceed with the use or disclosure, making sure that the information is not kept in a form which identifies this service user unless this is strictly necessary for the purpose and that all information is held under the highest levels of security.

If appropriate, make sure that this service user is informed of the purpose of any proposed disclosure, to whom their information will be disclosed, and what information is being disclosed.

NO

YES

Is there an overriding public interest in the purpose to be served by the proposed use or disclosure? (See 3.21)

NO

'Assess on a case by case basis whether the particular use or disclosure is necessary and how much disclosure is necessary.' (Proceed as in (C) on the following page)

YES

Is there a public interest in the health or social care purpose to be served by the proposed use or disclosure? (See 3.14)

NO

YES

Do not use or disclose

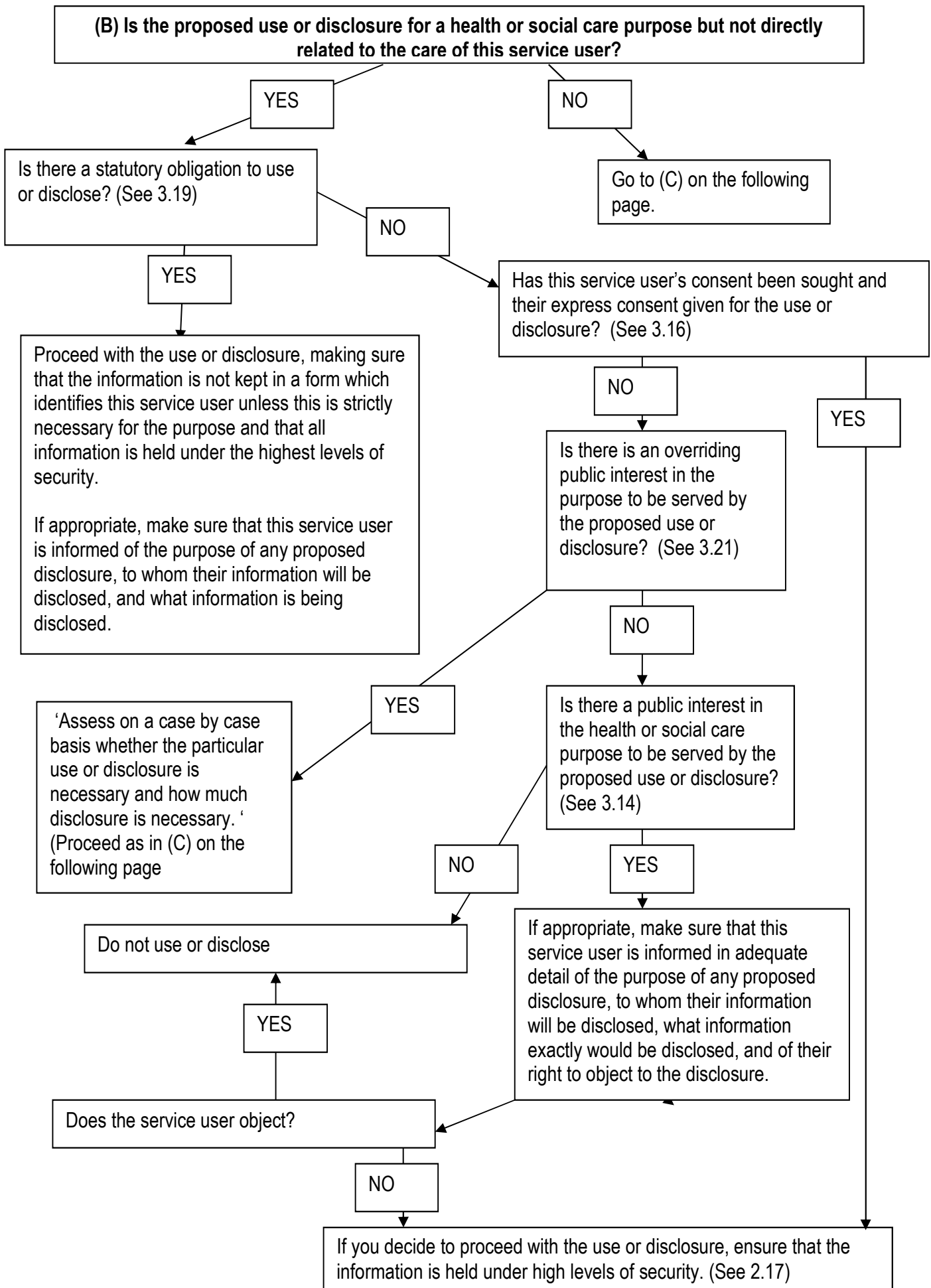
If appropriate, make sure that this service user is informed in adequate detail of the purpose of any proposed disclosure, to whom their information will be disclosed, what information exactly would be disclosed, and of their right to object to the disclosure.

YES

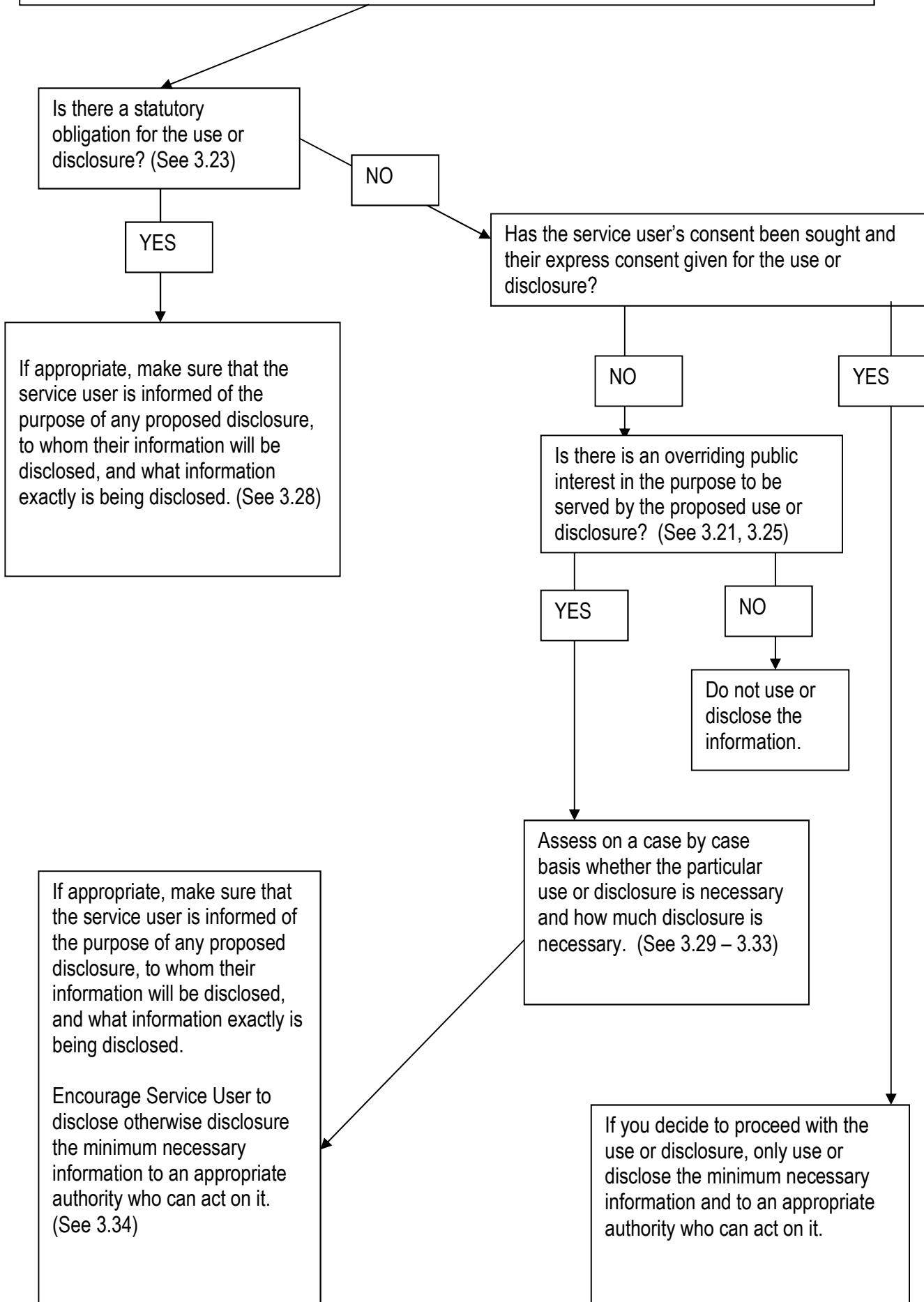
Does the service user object?

NO

If you decide to proceed with the use or disclosure, ensure that the information is held under high levels of security. (See 2.17)



(C) The proposed use or disclosure is for other purposes



SUMMARY

A. Direct Care

1. Service users must be informed in a manner appropriate to their communication needs of what information sharing is necessary for their care and the likely extent of the sharing for a particular episode of care.
2. In emergency situations uses or disclosures may be made, but only the minimum necessary information should be used or disclosed to deal with the emergency situation.
3. Review of care carried out by members of the care team and those supporting them have sufficient connection with that direct care for the sharing of information to be justified on the basis of implied consent, provided the individual has been informed
4. Where it is planned to involve staff from other agencies this should first be discussed with the service user and their explicit consent sought.
5. When other agencies request information about service users, health and social care staff should seek the consent of the service user.
6. In situations of ongoing need for care and support, the potential benefits of sharing information with their informal carers should be discussed with the service user.
7. The confidentiality of informal carers should be respected and information about them should not normally be disclosed without their consent.
8. Where a staff member has dual responsibilities it is important that they explain to the service user at the start of any consultation or assessment in what capacity they are seeing them and the purpose of the consultation or assessment.

B. Secondary Uses

9. All organisations seeking service user information for other than direct care should be seeking anonymised or pseudonymised data.
10. When the proposed use or disclosure of identifiable information relates to health and social care, but is not directly for the care of

that service user, the common law requires that the express consent of that service user should normally be obtained.

11. The possible exceptions to requirement for consent are where a statute, court or tribunal imposes a requirement to disclose or there is an overriding public interest in the use or disclosure.
12. Organisations should not use personal identifiable information for secondary uses if the service user in question has opted out by specifically refusing consent.

C. Use and disclosure for other purposes

13. Consent is not required where there is a statutory obligation to disclose or a discretionary disclosure is justified in the public interest.
14. Where a statute, court or tribunal imposes a requirement to disclose information, care should be taken only to disclose the information required to comply with and fulfil the purpose of the law.
15. In all cases of discretionary disclosure in the public interest there is no legal obligation to disclose, rather whether or not disclosure can be justified depends on balancing the interests that are in conflict in each case; for example protecting a third party from serious harm. The test is whether the release of information to protect the interests of a third party exceptionally prevails both over the duty of confidence owed to the service user and the public interest in a confidential health and social care service. Factors to consider when exercising a discretion are:
 - the nature and extent of the proposed disclosure;
 - the importance of the interest that is at risk without disclosure, for example disclosure might be more easily justified where the life or integrity (physical or psychological) of a third party is at risk;
 - the likelihood of the harm occurring in the individual case, that is, disclosure might be justified where there is a high likelihood of harm to the life of another, but not necessarily justified where there is a low likelihood of harm;
 - the imminence of the harm, that is, disclosure might be justified where protection of the third party requires immediate action, but not where there is no more than a

possibility that at some future point the service user might pose a threat to another;

- the existence of an appropriate person to whom disclosure can be considered;
- the necessity of the disclosure to avert the harm, that is, where there is no reasonable possibility of averting the harm without disclosure;
- the likelihood that disclosure can avert the harm, which requires that the health or social care staff member be satisfied that the harm to the third party or to the public interest is sufficiently likely to be averted by disclosure.

CHAPTER 4. Decision-making about whether to use or disclose personal information relating to adults lacking capacity

- 4.1 All service users have the right to the privacy of their health and social care information and this right is in no way diminished because a service user lacks decision-making capacity in some respect. The protection of the privacy interests of service users who lack capacity is in general in their best interests.
- 4.2 In general, a person with the capacity to make decisions about privacy issues should be able to:
- show understanding of the idea of disclosure of confidential information about themselves and of the possible implications of agreeing to the disclosure of information or of refusing it;
 - retain the information sufficiently to come to a decision;
 - believe the relevant information;
 - weigh the implications of disclosure in the balance to arrive at a choice;
 - communicate their decision.

It is important that capacity is assessed for particular decisions at particular times and, where possible, decisions should be postponed until a service user with fluctuating capacity is able to make the decision him or herself.

Keeping service users informed and seeking consent

- 4.3 In general if an adult with impaired capacity is able to take part in decision-making then they should be provided with an explanation of why it is proposed to use or disclose information and their consent sought (see paras 2.6 – 2.9 above).
- 4.4 Where an adult lacks capacity, decisions should in general be made in their best interests.

Information for direct care

- 4.5 Sharing information with the right people can help to protect individuals lacking capacity from harm and ensure that they get the help they need. It can also reduce the number of times they are asked the same questions by different professionals. As the requirements of implied consent are unlikely to be met (see para 3.4

above) asking for consent to share relevant information shows respect and involves the individual in decisions about their care.

- 4.6 Personal information should not be shared more widely than is strictly necessary, for example, in meetings with other professionals outside the Health and Social Care team, where without disclosure you would not be acting in their overall best interests.

Information for secondary uses

- 4.7 The same principles apply as for capacitous adults for all proposed uses and disclosures for health and social care purposes not directly related to that person's care. Where an adult lacks capacity to consent decisions should in general be made in their best interests (see para 4.12 below).

Disclosures in the public interest

- 4.8 Information required by statute, court order or a tribunal must be disclosed.
- 4.9 Information should be disclosed if it is necessary to protect an adult who lacks capacity or someone else from risk of death or serious harm. Such cases may arise, for example, if:
- the person is at risk of neglect or sexual, physical or emotional abuse;
 - the information would help in the prevention, detection or prosecution of serious crime, usually crime against the person;
 - the person is involved in behaviour that might put them or others at risk of serious harm, such as serious addiction, self-harm or joy-riding.
- 4.10 If disclosure is considered to be justified, the information should be disclosed promptly to an appropriate person or authority and the discussions and reasons relating to the disclosure should be recorded. If disclosure is not justified, the reasons for not disclosing should be recorded.

Protection of Vulnerable Adults

- 4.11 There can be conflict between protection and confidentiality. Both are extremely important in safeguarding the welfare of adults with incapacity. Health and social care staff can play an important role in protecting adults from abuse and neglect.
- 4.12 Confidentiality is important and information sharing should be proportionate to the risk of harm. Some limited information may need to be shared, with consent if possible, in order to decide if there is a risk that would justify further disclosures. Disclosing information is justified in raising a concern, even if the concern turns out to be groundless, if it is done honestly, promptly, on the basis of reasonable belief, and through the appropriate channels.

Determining 'best interests'

- 4.13 In determining the best interests of a service user who lacks capacity, particular consideration must be given as to how the opinions of others can be gained without inappropriately disclosing confidential information to them. Disclosing information to others to seek their opinion on the best interests of the service user may not itself be in the best interests of the service user.
- 4.14 In determining the best interests of a service user, the following should be considered:
- the service user's own wishes and values (where these can be ascertained), including any advance statement;
 - the effectiveness of the use or disclosure, particularly in relation to other options;
 - where there is more than one option, which option is least restrictive of the service user's future choices;
 - the likelihood and extent of any benefit to the service user if the use or disclosure is made;
 - the views of people close to the service user, especially close relatives, partners, carers or court appointed deputies about what the service user is likely to see as beneficial; and
 - any knowledge of the service user's religious, cultural and other non-medical views that might have an impact on the service user's wishes.

Carers and advocates

4.15 In some circumstances it may be appropriate to consult carers or independent advocates in considering what is in the best interests of a service user who lacks capacity. However, it is important to be clear on the limits of the ability of carers and advocates to legally represent the interests of the service user and the need to maintain the confidentiality of the service user with respect to them.

SUMMARY

1. If an adult with impaired capacity is able to take part in decision-making then they should be provided with an explanation of why it is proposed to use or disclose information and their consent sought, including consent to talk to others involved in their care or treatment.
2. Where an adult lacks capacity, decisions should in general be made in their best interests.
3. For direct care personal information should not be shared more widely than is strictly necessary.
4. For all proposed secondary uses the same principles apply as for capacitous adults. Where an adult lacks capacity to consent, decisions should in general be made in their best interests.
5. Information required by statute, court order or a tribunal must be disclosed.
6. Information should be disclosed if it is necessary to protect an adult who lacks capacity, or someone else, from risk of death or serious harm.
7. Protection of Vulnerable Adults. Confidentiality is important and information sharing should be proportionate to the risk of harm. Some limited information may need to be shared, with consent if possible, in order to decide if there is a risk that would justify further disclosures.

CHAPTER 5. Decision-making about whether to use or disclose personal information relating to children¹

5.1 Children have the same rights to privacy as all other persons and there is the same duty of confidentiality to them as there is to adults.

Keeping children informed and seeking consent

5.2 Children may have particular needs when it comes to the provision of information about uses and disclosures. It is important that the rights of children and young people are equally respected in this area and this may mean using different methods of providing information from those used for adults.

5.3 If a child is able to take part in decision-making then they should be provided with an explanation of why it is proposed to use or disclose information. Their consent should normally be sought, including consent to talk to parents and others involved in their care or treatment. Where a child is not competent to consent, the consent of a parent or person with parental responsibility should be sought.

5.4 Circumstances may arise where a child who lacks the capacity to consent discloses information on the understanding that their parents will not be informed. In such circumstances staff should try to persuade the child to involve a parent (unless to do so may put the child at risk). If they refuse and it is considered necessary in the child's best interests for the information to be shared (for example, to enable a parent to make an important decision, or to provide proper care for the child), relevant information may be disclosed to parents or appropriate authorities. Discussions and reasons for the decision about whether information is shared should be recorded in the case notes.

5.5 Children, young people and parents may not want their information to be disclosed if they think they will be denied help, blamed or made to feel ashamed. They may have fears about contact with the police or social services. They should be assisted in understanding the importance and benefits of information sharing.

¹ This section of the Code of Practice has been based on the GMC's "0-18 years: guidance for all doctors" (2007) – updated 8 April 2018. Legally, a 'child' is defined as someone under the age of legal majority. Legal majority is defined as the age of 18 years. The term child is used throughout this chapter to refer to children and young people under 18 years of age.

Access to a child's health and social care records

- 5.6 Children with capacity have the legal right to access their own health and social care records and can allow or prevent access by others, including their parents. Children should usually be supported in accessing their own records.
- 5.7 If a child consents, or lacks capacity, and it does not go against the child's best interests, parents should be given access to their child's health and social care records. If the records contain information given by the child or young person in confidence the information should not normally be disclosed without their consent, unless it would be necessary to disclose information for the reasons outlined in paragraph 5.8.

Information for direct care

- 5.8 Sharing information with the right people can help to protect children from harm and ensure that they get the help they need. It can also reduce the number of times they are asked the same questions by different professionals. Asking for consent to share relevant information shows respect and involves children in decisions about their care.
- 5.9 The views and wishes of a child (and where appropriate their parents) in relation to sharing confidential personal information should be sought, and their position on the matter recorded. Consent must always be meaningful. It may be necessary to share confidential information with staff from other statutory and voluntary organisations and with other individuals to safeguard or protect the best interests of a child, for example in the context of a child protection investigation. In these circumstances, there is no requirement to seek the consent of the child. An explanation for the decision to share information should be provided to the child (and parents as appropriate) and noted in the file record. As in all instances, the nature and details of the confidential personal information shared should be proportionate to the context and in line with the best interests of the child.

Information for secondary uses

5.10 The same principles apply as for adults for all proposed uses and disclosures for health and social care purposes not directly related to that child's care. Where a child lacks capacity to consent, the consent of a parent or appropriate authority should be sought.

Disclosures in the public interest

5.11 Information required by statute, court order or a tribunal must be disclosed.

5.12 Information should be disclosed if it is necessary to protect the child or someone else from risk of death or serious harm. Such cases may arise, for example, if:

- a child is at risk of neglect or sexual, physical or emotional abuse;
- the information would help in the prevention, detection or prosecution of serious crime, usually crime against the person;²
- a child is involved in behaviour that might put them or others at risk of serious harm, such as serious addiction, self-harm or joy-riding.

5.13 If disclosure is considered to be justified, disclose the information promptly to an appropriate person or authority and record your discussions and reasons. If disclosure is not justified, record your reasons for not disclosing.

Protection of children

5.14 Health and social care staff play a crucial role in protecting children from abuse and neglect. Staff may be told or notice things that others may not and may have access to confidential information that causes them to have concern for the safety or well-being of children. The assessed levels of actual or potential harm to a child, as well as the substance and imminence of such harm, should inform decision-making with regard to the sharing of personal identifiable information. The welfare of the child is paramount. Where there is concern that a child or young person is at risk of abuse or neglect, staff should make a referral to the Child Protection/Gateway Service² (which will determine whether any further action is

² The Gateway Service for Children's Social Work is the first point of contact for people who wish to share a concern about a young person who is not already known to social services

required) unless the increased risk to the safety or welfare of the child is deemed to clearly outweigh the benefits of sharing information through such a referral. Where a child is considered to be at immediate risk of serious harm, this information should be reported to the police. If a child or young person with capacity objects to information being disclosed, staff should consider the child's or young person's reasons and carefully weigh the possible consequences of not sharing the information against the harm that sharing the information might cause.

- 5.15 Disclosing information is justified in raising a concern, even if the concern turns out to be groundless, if it is done honestly, promptly, on the basis of reasonable belief, and through the appropriate channels.
- 5.16 The protection of children from harm is in the public interest and can legally justify breaching confidentiality in certain situations. Sharing relevant information with an appropriate person or authority should not be delayed if to do so would increase the risk of harm to the child or young person or to other children or young people. Any decision to share personal or sensitive information without consent, and the reasons for doing so, must be clearly recorded.

SUMMARY

1. Children have the same rights to privacy as all other persons and there is the same duty of confidentiality to them as there is to adults.
2. Where there is concern that a child or young person is at risk of abuse or neglect, staff should make a referral to the Child Protection/Gateway Service unless the increased risk to the safety or welfare of the child is deemed to clearly outweigh the benefits of sharing information through such a referral. Where a child is considered to be at immediate risk of serious harm, this information should be reported to the police. If a child or young person with capacity objects to information being disclosed, staff should consider the child's or young person's reasons and carefully weigh the possible consequences of not sharing the information against the harm that sharing the information might cause.
3. If a child is able to take part in decision-making then they should be provided with an explanation of why it is proposed to use or disclose information.
4. A child's consent should normally be sought, including consent to talk to parents and others involved in their care or treatment.

5. Where a child is not competent to consent, the consent of a parent or person with parental responsibility should be sought.
6. For all proposed secondary uses the same principles apply as for adults. Where a child lacks capacity to consent, the consent of a parent or appropriate authority should be sought.
7. Information required by statute, court order or a tribunal must be disclosed.
8. Information should be disclosed if it is necessary to protect a child, or someone else, from risk of death or serious harm.
9. Child protection. Disclosing information is justified in raising a concern, even if the concern turns out to be groundless, if it is done honestly, promptly, on the basis of reasonable belief, and through the appropriate channels.

Further Information

- 5.17 Further information about the legislation, policies and procedures relating to the protection of children in Northern Ireland can be found in the following links:

[Co-operating to safeguard children and Young People in Northern Ireland](#) Department of Health, 2017. This provides the overarching policy framework for safeguarding children and young people in the statutory, private, independent, community, voluntary and faith sectors. It outlines how communities, organisations and individuals must work both individually and in partnership to ensure children and young people are safeguarded as effectively as possible.

[Safeguarding Board for Northern Ireland \(SBNI\) Procedures Manual](#) The SBNI has a statutory duty to develop policies and procedures for safeguarding and promoting the welfare of children. The Procedures Manual explains the actions that must be taken when there are concerns about the welfare of a child or young person.

[Guidance to agencies: public protection arrangements](#) Department of Justice, 2017

[Sharing to safeguard: information sharing about individuals who may pose a risk to children](#) Circular HSS CC 3/96 (revised). Department of Health, 2009.

[This revised circular provides](#) a framework for agencies to inform decision-making in respect of individuals who pose or may pose a

risk to children or vulnerable adults. This circular is currently under review, but remains extant at the present time. Staff should be aware that the disclosure of information to third parties about individuals of concern in cases involving children/ young people has been the subject of a number of judicial decisions. The Department of Health issued guidance in 2013, with an addendum in 2014, to draw attention to relevant Judicial Review judgements which should be considered when making a decision about whether to share information about individuals who pose a risk to children.

This additional guidance is available as part of the SBNI's Procedures Manual at

http://www.proceduresonline.com/sbni/files/app1_outcome_review.pdf and

http://www.proceduresonline.com/sbni/files/app2_revision_info_share.pdf

Appendix 1:

The Principal Laws Relating to Confidentiality and Disclosure

Legal and ethical protections apply both to any *disclosure* of service user information and to any *use* of it. Legal obligations to protect the privacy of service users stem from three main sources:

- Common law of confidentiality
- Human rights law
- Data protection law

The requirements of the legal standards may differ. It is important to note that meeting the obligations of one source does not guarantee that the obligations under the others are being met. For example, the consent of a service user for a particular use may not be required by data protection law, but may be a common law requirement.

The interaction of laws relating to privacy and confidentiality with other laws should be considered when necessary. In particular, additional legal requirements may apply when the service user is a child or young person or an adult who lacks capacity.

The pressures from outside health and social care for health and social care information can change in differing social, economic and political climates. It is important that the wishes and interests of service users remain at the heart of health and social care. The limits on policy and legislation set by human rights law are important protections for service users and the duty to act in keeping with their human rights obligations is a highly important duty of all health and social care staff.

GENERAL LAWS

The common law

The key principles of the law of confidentiality are contained in the common law, that is, in the decisions of judges in particular cases. A duty of confidence arises when information which is clearly confidential comes into a person's possession or where confidential information comes to the knowledge of a person (the confidant) in circumstances where that person has notice, or is held to have agreed, that the information is confidential, with the effect that it would be just in all circumstances that he or she should be precluded from disclosing the information to others. The relationship between a health or social care provider and a user of those services constitutes such a circumstance. In the event of a breach of this duty of confidence, legal action may follow, including claims for an injunction and/or damages. However, the user of health and social care services can consent to the disclosure

of information. In addition, disclosure may in certain circumstances be justified on the grounds that it is in the public interest (e.g. to help the police investigate a serious crime). Health and social care professionals should not, of course, obstruct police investigations, because that is itself a crime, but before making a disclosure they must satisfy themselves that it is sufficiently in the public interest to warrant waiving their duty of confidentiality. If they are not certain of this, confidentiality should be preserved and the reason for the decision should be explained to the police, who may then ask a judge to issue a witness summons on the basis that the public interest requires disclosure.

Human Rights Act 1998

The Human Rights Act 1998 incorporates the main Articles of the European Convention on Human Rights into the domestic law of all parts of the United Kingdom. The Human Rights Act obliges all public authorities to protect people's Convention rights and requires all other legislation to be applied, if possible, in a way which protects those rights. Article 8(1) of the European Convention states that: 'Everyone has the right to respect for his private and family life, his home and his correspondence.' To date this provision has not been interpreted by judges in the United Kingdom as imposing a general right to privacy, but it has certainly been used to strengthen the right to confidentiality. The Convention itself recognizes limits to the right conferred by Article 8(1). Thus Article 8(2) provides:

There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

This means that any decision concerning the disclosure of confidential information about a user of health or social care services without his or her consent requires an analysis of whether the decision to disclose is 'proportionate'. The extent of disclosure should be proportionate to the purpose being fulfilled by the disclosure and should extend only as far as is necessary to achieve that purpose.

The General Data Protection Regulation and Data Protection Act 2018

The Data Protection Act 1998 has been replaced by the General Data Protection Regulation (GDPR) and the Data Protection Act 2018 (DPA18).

The following is an extract from the IGA guidance, to which PAC was a contributor. That guidance will be kept up to date in light of any relevant guidance issued from Government and the Information Commissioner's Office (ICO).

The GDPR requires that organisations (controllers) that process personal data demonstrate compliance with its provisions. Part of this involves establishing and publishing a basis for lawful processing, and where relevant, a condition for processing special categories data.

Key messages

- 1) Under the GDPR organisations (controllers) must establish, record and inform subjects about the lawful basis that they are relying on to process personal data.
- 2) For health and social care organisations to process personal data, one of the lawful bases for processing data set out in Article 6 must apply.
- 3) To process special categories of personal data, one of the bases for processing data set out in Article 9 must also apply.
- 4) To process data relating to criminal convictions and offences, the lawful bases for processing will be set out in the DPA18 as permitted by Article 10.
- 5) Consent is one way to comply with Article 6 of the GDPR, but it is not the only way, and in many health and social care contexts obtaining GDPR-compliant consent (which is stricter than that required for confidentiality) may not be possible.
- 6) Organisations should consider relying on the alternatives to consent for GDPR purposes, taking into account that different individuals' rights provided by the GDPR are engaged depending on which basis for processing is chosen. Generally individuals have more rights where consent is relied on as the basis for lawful processing under the GDPR.
- 7) Publicly funded health and social care organisations which are public authorities for the purposes of The Freedom of Information Act (FOIA) 2000 will be public authorities for the purposes of the GDPR and they must no longer use 'legitimate interests' as their basis for lawful processing – in the performance of their tasks.
- 8) The most appropriate basis for lawful processing that is available to publically funded and/or statutory health and social care organisations in the delivery of their functions is: 6(1)(e) '...for the performance of a task carried out in the public interest or in the exercise of official authority...'
- 9) There are a number of lawful bases for processing special categories of personal data that may be available to health and social care organisations, as set out in Article 9 of the GDPR.

For further information please consult the IGA website:

[digital.nhs.uk Information Governance Alliance](https://digital.nhs.uk/information-governance-alliance)

SPECIFIC LAWS

HSC (Control of Data Processing) Act 2016

Informed consent is the fundamental principle governing the use of patient identifiable information within health or social care. It is recognised that there are situations where informed consent cannot be obtained. Where consent is not a practicable alternative and where anonymising information will not suffice the Health and Social Care (Control of Data Processing) Act 2016 will provide a new statutory power enabling service user identifiable information to be used to support essential Health and Social Care, provided there is a clear public interest to do so. Under the Act where a service user has indicated their wish to opt-out of their information being shared their wishes must be respected. However enacting regulations remain to be developed and therefore the legislation is not yet in force.

Criminal Law Act (NI) 1967

Section 5 of this Act imposes a duty on every person who knows or believes that an arrestable offence has been committed – and that he or she has information which is likely to secure the apprehension of someone for that offence – to give that information, within a reasonable time, to the police. An arrestable offence is defined as one for which a person can be sent to prison for five years or more (i.e. a fairly serious offence). However, a person can be charged with an offence under section 5 only if the Director of Public Prosecutions consents to this. Moreover a person who has been charged with the offence can plead by way of defence that he or she had a ‘reasonable excuse’ for not providing the information to the police. It is *possible* that a court would accept the public interest in preserving the confidentiality of service user information as a reasonable excuse for a professional in the health or social care sectors not passing on information about a crime to the police.

Public Health Act (NI) 1967

Under section 2 of this Act every medical practitioner attending on a person must, as soon as he or she becomes aware, or has reasonable grounds for suspecting, that that person is suffering from a notifiable disease, send to the Director of Public Health of the Health and Social Services Board for the area in which the examination took place a certificate stating (a) the name, age, sex and address of the patient, (b) the address of the building in which the

examination took place, and (c) the notifiable disease from which, in the opinion of the medical practitioner, the patient is, or may be, suffering.

Note this legislation was amended in the Health and Social Care Act 2009 – Article 2.4(1) changes reporting responsibility from the old HSSB to the Regional Agency (PHA).

National Health Service (Venereal Diseases) Regulations 1974

These Regulations impose a duty on health authorities in Northern Ireland to ensure that information about venereal diseases obtained by their officers is treated as confidential. In 1991, Directions were made imposing the same obligations on trustees and employees of an NHS Trust.

Health and Safety at Work (NI) Order 1978

Articles 29, 29A and 30 of this Order regulate the duty to provide information in connection with the maintenance of health and safety in places of work. Generally speaking, no relevant information can be disclosed without the consent of the person by whom it was furnished, but there are exceptions for disclosure to, for example, a government department, an enforcing authority or the police.

Mental Health (NI) Order 1986

A psychiatrist who is arranging admission to a hospital under this Order is required to share relevant information with the approved social worker. The approved social worker must then consult with the nearest relative. Where the nearest relative requests discharge from hospital and the responsible medical officer issues a barring order, the responsible Board of the hospital is required to inform the nearest relative that the patient would be liable to act in a manner dangerous to others or to him- or herself. The Mental Health Review Tribunals can also access patients' records.

Note this legislation was amended in the Health and Social Care Act 2009 – Section 2(1) changes responsibility for informing the nearest relative from “the responsible Board of a hospital” to either a Health and Social Care Trust or the Regional body (HSCB).

AIDS (Control) (NI) Order 1987

This Order imposes a duty on each health board in Northern Ireland to issue regular reports on the number, but not the names, of people diagnosed with AIDS and those who are HIV positive.

Human Fertilisation and Embryology Act 1990

This Act requires the Human Fertilisation and Embryology Authority, in particular circumstances, to disclose certain information it has recorded on a register it must keep. Some restrictions on the Authority's right to disclose were removed by the Human Fertilisation and Embryology (Disclosure of Information) Act 1992. Provisions were made under the HFE Act 2008 for information to be disclosed for research purposes either with consent or with support under the HFE (disclosure of patient information for research purposes) 2010 - SI 995.

Police and Criminal Evidence (NI) Order 1989

Article 10 empowers the police to enter premises under a warrant issued by a magistrate to conduct a lawful search. The police can seize items if they are covered by the warrant or if there are reasonable grounds for believing that the items are evidence of an offence, but only if seizure is necessary to prevent the items being concealed or tampered with. Medical records, however, are within the definition of 'excluded material'. Generally speaking the police can gain access to and seize excluded material only after being granted permission by a judge. Where the police cannot rely on these statutory powers they may still make requests for disclosure of confidential documentation. In such instances health and social care professionals must decide whether it is in the public interest to disclose the confidential information to the police.

Criminal Appeal Act 1995

Section 17 states that where the Criminal Cases Review Commission (whose function is to identify miscarriages of justice) believes that a person serving in a public body has possession or control of a document or other material that may assist the Commission, the Commission may direct that person to produce the document or material to the Commission or to allow access to it. The Commission also has the power to order that the document or material must not be destroyed or altered. The duty to comply with the Commission's direction is not affected by any obligation of secrecy or other limitation on disclosure which would otherwise prevent the disclosure of the document or material.

Terrorism Act 2000

Under section 19 a professional person or employer commits a criminal offence if he or she does not disclose to the police – as soon as is reasonably practicable – his or her belief or suspicion, and the information on which it is based, that another person has committed an offence relating to the funding of terrorism or to the use of property for the purposes of terrorism. However, it is a defence for a person charged under section 19 to prove that he or she had a reasonable excuse for not making the disclosure. The Anti-terrorism, Crime and Security Act 2001 extends the disclosure requirements so that they apply even to terrorist investigations and proceedings being conducted outside the United Kingdom.

Serious Crime Act 2007

This Act amends the Audit and Accountability (NI) Order 2003 to give power to the Comptroller and Auditor General for Northern Ireland to conduct data matching exercises in order to assist in the prevention and detection of fraud. Data about patients can be used in data matching exercises only if the Comptroller requires it to be supplied by a body – such as a health board – whose accounts have to be audited by the Comptroller. In such cases the processing of data does not require the consent of the individuals concerned, but it must otherwise comply with the Data Protection Principles set out in the Data Protection Act 2018.

Appendix 2: The Ethics of Confidentiality

Ethical standards for the protection of service user information may be higher than legal standards. Even where legal obligations are satisfied, a particular use or disclosure may not necessarily be ethical. Where ethical standards require greater protection for service user confidentiality than legal standards, then health and social care staff should follow professional ethical obligations.

It is important to note that disciplinary consequences may follow from a breach of ethical standards set by regulatory authorities.

The nature of the obligation to protect confidentiality can be expressed in terms of three core principles:

- Individuals have a fundamental right to the confidentiality and privacy of information related to their health and social care.
- Individuals have a right to control access to and disclosure of their own health and social care information by giving, withholding or withdrawing consent.
- For any disclosure of confidential information health and social care staff should have regard to its necessity, proportionality and any risks attached to it.

Just as the service user has a right to self-determination in various other health and social care matters, it is in general the service user's decision as to who should have access to personal health and social care information and the purpose for which it may be used.

One reason for respecting confidences in health and social care is that doing so enables service users to disclose sensitive information that health and social care staff need to provide treatment or care. Without an assurance that confidentiality will be maintained, service users might be less willing to disclose information, resulting in obstacles to their effective care and negative effects for their health and for public health.

None of the ethical arguments stated above lead to the conclusion that the ethical duty of confidentiality is absolute. The confidentiality requirement exists within a wider social context in which members of staff have other duties which may conflict with their duty of confidentiality. In particular, they may have other ethical duties to disclose confidential information, without consent, if serious dangers are present for third parties or for the service user and where they judge that the disclosure of that information is likely to significantly reduce or eliminate the danger. In assessing such risks and whether they outweigh the

duty of confidentiality both the probability of the harm and its magnitude need to be considered. The ethical duty to disclose to prevent harm is generally greater when both the probability and the seriousness of harm to a third party or the service user are high.

Appendix 3

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