Information Sharing and Mental Health

Guidance to Support Information Sharing by Mental Health Services
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Purpose

1. This guidance sets out some of the opportunities and constraints involved in the exchange of information between health services and statutory and non-statutory organisations, as well as between health services and individuals.

2. It is intended for people working in mental health care and for those interested in these services. It aims to set out when, why and with whom information can be shared.

3. This guidance considers those circumstances in which there is a conscious decision to share information in the best interests of the individual and wider society. It is not intended to cover the overriding duty of NHS staff to ensure that patient data is handled in accordance with the NHS Code of Practice on confidentiality.¹

4. All NHS staff need to be particularly careful to protect personal data from unauthorised access through the use of encryption and the careful custody of any written or electronic records. Trust boards have an unambiguous responsibility for ensuring that the handling of personal data within their organisations is appropriately risk managed.

5. In addition, the public have a right to expect that information given in confidence is treated as such and that every NHS employee will play his or her part in fulfilling that responsibility.

6. Information sharing is a fundamental tool in the delivery of safe and effective services and is one for which senior managers need to take personal responsibility and ownership.

Government policy is clear. We need to share appropriate information between organisations and professionals to ensure that people get the services they need.

Occasionally, we might need to disclose personal information as part of our wider obligation to protect the general public.

There is not a conflict between information sharing and security. The ability to share appropriately is a fundamental part of data security.

Delivering care to the more vulnerable people in society means bringing together skills and resources from the public, voluntary and other sectors.

A reluctance to share information because of fear or uncertainty – about the law or the lack of suitable arrangements to do so – has been a feature of some public services in recent years and a factor in numerous accounts of untoward incidents, including homicides. A natural reaction to uncertainty is to take what appears to be the least risky option and, for information sharing, that can often mean doing nothing – and that may be the worst outcome for the individual and the public.

This is why it is so important that a senior person within each organisation is able to provide advice to all grades of staff who may be faced with making these decisions. The introduction of Caldicott Guardians (see page 18) into the NHS and into local authorities with social services responsibilities was explicitly designed to meet this need.

Recent legislation has tended to make information sharing seem complex. However, in this era of identity theft, internet fraud and increasingly sophisticated marketing, few would deny the need for laws to protect the privacy of the individual.

It can be too easy to see the law and guidance as impediments to information exchange, rather than as a framework in which this can take place safely. However, it was never intended that the needs of an individual

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2 www.foi.gov.uk/sharing/toolkit/lawguide.htm
or the wider needs of society should be impeded by legislation such as the Human Rights Act 1998 or the Data Protection Act 1998.

15. Instead, this legislation ensures that information can be shared in a way that is safe for everyone.

16. There are some clear guiding principles:
   - Sharing information about an individual is entirely lawful if specific informed consent is sought and given.
   - Even when such consent is not given, when protection of the individual and/or wider society is at stake, the sharing of information may be lawful and, sometimes, essential.
   - Unnecessary disclosure of personal information is wrong, on a number of counts.
   - Agreed protocols with other public bodies are important for clarifying mutual expectations and responsibilities.

All of this needs to take place in a context of safe and secure holding and processing of personal data.

17. Anonymised data can be shared with other agencies in order to help them identify where resources can be most usefully deployed. A good example of this is the way that the police can use A&E data to pinpoint where alcohol-related violence is taking place.

18. Appendix A provides an overview of the main legislation and guidance that underpins these principles. This document is not intended to provide an analysis of this legislation, nor to provide a definitive account. Rather, it is meant to advise staff who are faced with regular issues about information sharing.

The NHS and confidentiality

19. There is a dilemma unique to healthcare. People share their most intimate details with health professionals and do this on the assumption that they will not be shared beyond those responsible for delivering care to them.
20. In order to maintain confidence that information can safely be held by the NHS, Ministers issued The Care Record Guarantee in 2005. This has been regularly updated since then and makes 12 commitments, including:

“We will not share health information that identifies you (particularly with other government agencies) for any reason other than providing your care, unless:

• you ask us to do so;
• we ask and you give us specific permission;
• we have to do this by law;
• we have special permission for health or research purposes; or
• we have special permission because the public good is thought to be of greater importance than your confidentiality.”

21. The last point will very often depend on a judgement being made as to whether the public good outweighs the duty of confidentiality. It is not possible to set out in detail when the balance falls in favour of disclosure. There are easy examples at either end of the spectrum, for example: “I stole sweets from a shop 20 years ago” versus “I murdered my husband last night”. However, the reality is that most real-life examples will fall somewhere in the middle of these extremes and can be difficult to resolve.

22. The most straightforward route is through consent. This has to be both specific and informed. In other words, the person:

• needs to know what information is to be shared;
• needs to know with whom and for what purpose the information is to be shared;
• agrees to this in the absence of duress; and
• is capable of making such a decision.

3 www.nigb.nhs.uk/guarantee
23. The British Medical Association has issued guidance to members, balancing the need for disclosure and confidentiality. This states the following in relation to public interest disclosures:

“When considering disclosing information to protect the public interest, health professionals must:

• consider how the benefits of making the disclosure balance against the harms associated with breaching the patient’s confidentiality;

• assess the urgency of the need for disclosure;

• consider whether the person could be persuaded to disclose voluntarily;

• inform the patient before making the disclosure and seek his or her consent, unless to do so would increase the risk of harm or inhibit effective investigation;

• reveal only the minimum information necessary to achieve the objective;

• seek assurance that the information will be used only for the purpose for which it is disclosed; and

• be able to justify the decision.”

24. Similarly, the Royal College of Psychiatrists issued good practice guidance to their members that provides a wealth of useful detail covering a range of scenarios. It makes the point that a breach of confidentiality will only arise:

• “where the information has the necessary quality of confidence, i.e. it is private and is not in the public domain;

• where the information was imparted in circumstances that create an obligation of confidence; and/or

• where unauthorised use of the information would have a detrimental effect on the patient.”

25. It goes on to say that confidentiality can be overridden:

• by the patient giving consent to the disclosure;

• if disclosure is in the public interest; or

• where there is a statutory obligation.

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4  www.bma.org.uk
5  www.rcpsych.ac.uk/publications/collegereports/cr/cr133.aspx
26. Acting within frameworks of this sort, health bodies and individuals need to work with other public bodies and other sectors in the interests of society as a whole.

27. Appendix B provides an outline of the kind of agreement that public bodies should draw up between themselves to help ensure that this happens. There is not an ‘off-the-shelf’ agreement that can simply be adopted in any locality. The process of mutual understanding obtained by working through the issues can be almost as important for successful joint working as the contents of the agreement itself.
Who Needs Information?

Service users

28. Users themselves have a clear and unambiguous right to information that has an impact on their lives. They have a legal right to information held about themselves by public bodies and the presumption should always be that this should be made freely available. The only circumstances in which information should be withheld are:

- when this would be damaging to the health and well-being of the individual or others; or
- when there is information about a third party that needs to be withheld.

29. There are clear advantages in having well-informed service users, who are experts on their own condition, in a position to challenge the observations and views of those caring for them.

Carers

30. Carers have a large part to play in helping recovery and ensuring continued health. To do this, they need access to the right level of information. They frequently report feeling cut off from the care of an individual to whom they have provided considerable support. They may also need information for their own safety.

31. They may have information to offer, want advice on how to cope in the future, need help to access different services or simply want to know about progress and the outlook for the future. The advantage of sharing information with carers should be explained to the service user and, even if they are resistant to this when unwell, a further approach should be made when their health improves. However, it should be remembered that, unless there is an overriding reason, the wishes of the service user must be respected. A fuller discussion of this important topic can be found in Positive and Inclusive? Effective ways for professionals to involve carers in information sharing.\(^\text{6}\)

\(^{6}\) www.sdo.nihr.ac.uk/files/project/54-final-report.pdf
Voluntary sector

32. Similar considerations apply to those working in voluntary organisations who, increasingly, play a significant role in maintaining the health and well-being of people in the community. They are often able to act as advocates for people and populations, and play an important role as service providers. They, like carers, may also need information for their own safety.

33. In the provider role, they are entitled to the same level of information about an individual as would be expected by a statutory agency if they are to provide safe and effective services, and local agreements should facilitate this.

Statutory agencies

34. Statutory agencies also need to share information. Mental health care is commonly a shared responsibility between health and local authorities; joint access to client information is essential if that responsibility is to be fulfilled effectively.

35. Bodies such as housing authorities have an important part to play in helping people regain access to normal living and social inclusion, and they need to have appropriate information if they are to provide the right level of support and act in the interests of all of their residents and the wider population.

36. Some people may come into contact with both mental health services and the Criminal Justice System. This is not to say, except in a small number of cases, that mental health problems cause crime. Rather, both are closely associated with social exclusion and deprivation, which can be an antecedent and also a consequence of both criminal activity and mental health problems. The majority of those with mental health problems do not offend and, of those who do, the majority are neither violent nor dangerous.

37. Some detailed guidance and worked examples exist about information exchange between mental health services and the Criminal Justice System (e.g. London Risk Data Sharing Project, 2004, and local protocols between the police and health services, 2004).

7 www.socialinclusion.org.uk/publications/SEU.pdf
8 www.isb.gov.uk/hmt.isb.application.2/learners/case_studies.asp
38. There are a number of ways in which the Criminal Justice System and mental health services need to interact. When police come across someone acting unusually in a public place and have reason to believe that this may be due to mental disorder, they will need to work closely with mental health colleagues to ensure that the person gets the help they need.

39. The Mental Health Act 1983 (section 136) allows the police to take such a person to a “place of safety”. This could be within a mental health facility or a police cell. The choice of location needs to be dictated by a risk assessment and the way of arriving at this should be agreed locally, usually as part of the agreement outlined in Appendix B. The Code of Practice to the Mental Health Act contains guidance on places of safety.¹⁰

40. If someone who may have a mental health problem is taken into custody or appears in court, it is important that information is exchanged. This is necessary to ensure that those who need care receive it and that the criminal justice authorities can take the individual’s mental health into account in determining the appropriate outcome.

41. In most areas of the country, there are Criminal Justice Liaison Schemes, operating either at police stations or courts, or both. When these are operating effectively, there are considerable benefits to the individual and to the smooth running of the judicial process. An explicit and agreed approach to information sharing is a critical determinant of the effectiveness of these partnerships.

42. When an offender with a mental health problem is serving a community sentence, or has been released from custody, probation staff can be in the position of supervising people who are either receiving mental health care or are in need of such care. These probation staff need regular contact with the appropriate health workers to ensure that they are fulfilling their public protection duties.

43. There are also instances when a patient goes missing from a mental health unit who may be a danger to themselves or others. The police need to be informed when this is the case and where there is significant cause for concern. It is important that the police are also informed when, as often happens, someone returns of their own accord.

¹⁰ www.dh.gov.uk/en/healthcare/mentalhealth/DH_4132161
44. The development of Multi-Agency Public Protection Arrangements\(^\text{11}\) (MAPPA) and, more recently, Multi-Agency Risk Assessment Conferences\(^\text{12}\) has provided worked examples of how agencies can cooperate in the best interests of the individual and society.

### Colleagues

45. The reports into the conduct of Shipman,\(^\text{13}\) Kerr and Haslam\(^\text{14}\) highlight the apparent reluctance of individuals to raise concern about the conduct of colleagues. They also raise the issue of responding appropriately to concerns raised by service users about those caring for them.

46. Thankfully, this culture seems to be changing, but it is essential that NHS organisations have clearly stated policies that encourage the sharing of such information and ensure that whistleblowers are given the support that they need and deserve.

### Victims

47. The needs of those adversely affected by the actions of someone with a serious mental health problem – ‘victims’ in the widest sense of the term – also need to be taken into account.

48. The NHS fully recognises the distress that can be caused to others by people with mental health problems. Some may feel threatened by a neighbour or relative with some form of socially disruptive mental illness. Others may be the victims, or be close to a victim, of crime, or may be the relative or friend of a person exhibiting such behaviour.

49. Health professionals should, of course, act as sensitively as possible to those who find themselves in this position, but they need to act within the law and there are very real constraints. The key here is consent. Many people who cause problems to others when mentally unwell will readily consent to specific disclosure as their mental state improves.

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12 [www.crimereduction.homeoffice.gov.uk/domesticviolence/domesticviolence066.htm](http://www.crimereduction.homeoffice.gov.uk/domesticviolence/domesticviolence066.htm)


50. The Domestic Violence, Crime and Victims Act 2004\textsuperscript{15} provides that the Victim Contact Scheme, managed by the Probation Service, will offer a service to victims of mentally disordered offenders where the offender has been ordered to be detained in hospital, or is transferred there from prison. Victims will have the opportunity to be informed of and, to some extent, involved in decisions made by the Home Secretary or Mental Health Review Tribunal about the conditions of the patient’s discharge. This only applies to patients subject to special restrictions and only applies to those sentenced or otherwise disposed after July 2005. The Mental Health Act 2007 extends this to a wider group of detained patients and places responsibility for liaison on hospital managers. This is the only legislation that mandates disclosure of such information about NHS patients.

51. Although we do need to act within the law, it is worth repeating that the disclosure of information, with consent, is rarely problematic. As well as providing reassurance to the victim, and potentially adding to the information available to the clinical team, such disclosure can be beneficial to the individual. Most people will return to the communities in which their behaviour gave rise to concern when it is safe for them to do so. That return is likely to be facilitated by the availability of information to carefully selected individuals, which allows those around them to have a realistic understanding of the risks involved.

52. We must also remember that, although not the direct responsibility of the team supporting the service user, the victim or victims may well have unmet needs, and consideration should be given to how meeting these needs could be achieved.

\textsuperscript{15} www.opsi.gov.uk/ACTS/acts2004/20040028.htm
Mental health professionals have duties that are sometimes felt to be contradictory. Rightly, they are proud of their inheritance of high standards of confidentiality and respect for the people for whom they care. On the other hand, they have a clear duty of care towards the individual and the wider public.

That dilemma may not be as difficult as it first appears. Sharing information about an individual is not a problem if informed consent is sought and given. It may be that we do not ask or pose the question at the right time or in the right context.

A theoretical example

Jim is well known to local mental health services. He suffers from schizophrenia and copes well when he takes his medication regularly. However, he does not like the side effects and is prone to stop taking it. When this happens, he believes that various people are about to cause him harm and can become very noisy and disruptive to his neighbours. He can be quite frightening, although he has never actually harmed anyone.

It took a couple of weeks to get Jim into hospital this time, and the neighbours are talking about petitioning the council to have him evicted. It would not be in his long-term interests to lose this tenancy, and it is clear to the care team that it would be helpful if someone could explain the situation to his neighbours. There would be no need to go into great detail about his condition but it may make Jim’s neighbours more tolerant, and perhaps let them know what they should do in future if the problem recurs.

If we ask Jim’s permission to do this when he is first admitted, he is likely to refuse. Similarly, if we ask the question out of context without explaining our reasons, he may also refuse.

But, when he is better and looking forward to going home, he may well agree that a discussion between his immediate neighbours and the care team would be beneficial to all involved.
55. However, unnecessary disclosure of personal information is always wrong. What someone needs to know is not the same as what they would like to know. The underlying rule is to be clear about the reasons why information is being shared and to restrict the information to that which is relevant to that purpose.

56. When regular exchanges of information need to take place between different agencies, it is important to have a formal agreement in place to ensure that everyone understands what information will be exchanged, for what purpose, and to whom.

57. Appendix B shows the typical content of this kind of agreement or protocol.
Appendix A: The Legislative and Guidance Framework

1. There is a considerable amount of legislation and guidance that aims to protect people from improper sharing of information about them, as well as common law, developed through case law.

2. The result of this can be to emphasise what cannot be done at the expense of being clear about what is allowable; health professionals can become uncertain about when, how and with whom it is appropriate to share information about an individual. In reality, legislation places few constraints on anyone acting in good faith and exercising good judgement.

3. It should be remembered that, in most instances, concern relates to information sharing in the absence of consent. When specific consent is sought, and freely given, few problems are likely to arise and health professionals can be confident that they are acting within the existing law and guidance. However, it must always be remembered that consent needs to be specific to the situation, information needs to be relevant and, in some circumstances, there may be a need to know what will happen to that information thereafter.

4. This guidance cannot be a comprehensive statement of the law or provide an answer in all eventualities. It is meant to provide an accessible guide to an area that many find challenging and to assist in the drawing up of the local agreements between organisations that are necessary to ensure that the needs of local people are met.

5. We will consider briefly the main implications of each piece of legislation and guidance.

Data Protection Act 1998 (DPA)

6. The Data Protection Act 1998 is the result of a European Directive that all the EU’s member states have been obliged to implement into their own law. There is, as a result, a common data protection framework across the EU. It provides a legal framework to ensure that personal information is properly protected.
7. The DPA only covers the processing of personal data stored electronically on a computer and some data stored in manual files from which data can be readily located.

8. Information relating to the physical or mental health, or condition, of an individual will constitute sensitive personal data. Sensitive personal data is awarded additional protection under the DPA. Information relating to mental health will therefore fall into this category. The DPA has eight principles with which data controllers (in effect, public bodies) are required to comply. Some of these will have more of a bearing than others on the processing of personal data in terms of information sharing and mental health. The first principle states that personal data should be processed fairly and lawfully.

9. The second data protection principle may also prove particularly pertinent to the sharing of mental health data: it states that personal data should be obtained for one or more specified and lawful purposes, and not further processed in a manner incompatible with that purpose or those purposes.

10. The third principle, which states that personal data ought to be adequate, relevant and not excessive, and the fourth principle requiring accuracy, will obviously be significant, whether information is disclosed to another party or not.

11. Dependent on the circumstances, there may also be an exemption to some or all of the principles. In the context of mental health and in particular offenders, the most likely would be section 29(a) or (b). This creates an exemption for personal data processed for:
   - the prevention or detection of a crime; or
   - the apprehension or prosecution of offenders.

12. Section 35 may also be relevant in certain circumstances. This also provides an exemption to the non-disclosure provisions where disclosure is required by law or is made in connection with legal proceedings.
Human Rights Act 1998

13. Article 8 of the Human Rights Act covers an individual’s right to privacy. A key sentence is:

“Everyone has the right to respect for his private and family life, his home and his correspondence.”

14. This right is not absolute, but a breach of it must be justified. In order to justify interference, the public authority will need to show that it acted:

- in accordance with the law;
- in the pursuit of a legitimate aim; and
- in a way necessary in a democratic society.

15. In practice, these criteria are readily met by anyone acting with good faith and in the public good. Consistently, courts have taken the view that they would only interfere if the decision to disclose information was palpably unreasonable and disproportionate to the circumstances.

Confidentiality: NHS Code of Practice

16. This document outlines the legal requirements and reiterates the NHS ethos of providing a confidential service. It acknowledges that there are exceptional circumstances in which information may be released without consent, but is largely concerned with ensuring that NHS data handling procedures are within the legal framework.

17. Patients’ identifiable information is held under a duty of confidentiality. This includes information about their condition, and where they are being treated. This means that such information should not normally be disclosed to anyone, unless the patient concerned has consented. In the absence of consent, confidentiality can only lawfully be breached if there is:

- a legal obligation to do so where the professional has no choice, e.g. a court order requiring disclosure; or
- an overriding public interest in disclosing the information where the professional must exercise judgement.

16 www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf
18. Unless the patient consents, this means that the person considering disclosure must be satisfied that there is an overriding public interest which justifies breaching the relevant patient’s confidentiality.

19. When considering a disclosure of confidential information, a judgement will always be required about where the public interest lies; the more private and damaging the information, the stronger the public interest in disclosure will need to be. Disclosure of health information is particularly likely to cause harm and/or distress because of its very personal nature. Any disclosures must therefore be necessary and proportionate.

20. The Code of Practice advises that:

“.. staff are permitted to disclose personal information in order to prevent and support detection, investigation and punishment of serious crime and/or to prevent abuse or serious harm to others where they judge, on a case by case basis, that the public good that would be achieved by the disclosure outweighs both the obligation of confidentiality to the individual patient concerned and the broader public interest in the provision of a confidential service.”

**Caldicott Guardianship**

21. Every statutory health and social services body is required to nominate a senior officer, known as the ‘Caldicott Guardian’, who is responsible for ensuring that the organisation complies with its duties under common law and the DPA. They should ensure that sound local policies are in place. Caldicott Guardians should be the first point of contact for advice on how to interpret the DPA’s requirements, and should provide local policy guidance on the circumstances in which confidentiality may be breached, and on when service users may access their own personal records.

**Professional guidelines**

22. Doctors, nurses, social workers, psychologists and occupational therapists all have specific guidelines or a section of a more general code covering confidentiality. These are generally consistent in that they emphasise the need for confidentiality, the importance of consent, and the limited range of circumstances in which information can be divulged without consent.
Multi-Agency Public Protection Arrangements (MAPPA) and the duty to cooperate

23. The Criminal Justice and Court Services Act 2000 established formal arrangements for the supervision of people in the community, which required police and probation authorities to involve health in the arrangements. Subsequently, through the Criminal Justice Act 2003 this became a “duty to cooperate” on health and other agencies. Strictly speaking, this is a duty to cooperate with a process rather than to divulge information about a particular individual, although such disclosure may be required in some cases. The latter is usually, and correctly, subject to detailed local agreements.

24. It should be remembered that nothing in the MAPPA places a new duty on clinicians or cuts across other legislation or guidance. However, it has been the experience of many, that the establishment of effective working relationships, and the development of innovative practices such as Single Points of Contact to allow the exchange of information in urgent situations at any time of the day or night, have improved both patient care and public safety.

Children Act 2004

25. The Children Act is the legal framework under which local authorities exercise their responsibility for the care and protection of children. In this context, it places a duty on local authorities to make enquiries of other public bodies if they suspect that a child is at risk. It also places a duty on these bodies to comply with such a request. Like MAPPA, this does not cut across other legislation or guidance, and the decision-making processes described in this document continue to apply.

Crime and Disorder Act 1998

26. There is provision in the Crime and Disorder Act that specifically allows police, local and health authorities to disclose information about individuals on the sex offender register who have also been identified as posing a significant risk to others.

27. Section 115 of the Act allows agencies or individual professionals to share information about victims of domestic abuse who may be deemed to be at significant risk.
Domestic violence guidance

28. In a document entitled *Safety and justice: sharing personal information in the context of domestic violence – an overview*, a number of government departments came together to produce a document to clarify information sharing in the context of domestic violence.

29. It helpfully points out that in the context of domestic violence – which claims the lives of two women a week in the UK – the Human Rights Act places an obligation on public bodies to protect individuals. Articles 2 and 3 deal with the right to life and freedom from torture and inhuman and degrading treatment. These considerations can give rise to the need for information exchange between agencies, and override Article 8 (the right to privacy in circumstances where someone is at risk).

17 www.crimereduction.homeoffice.gov.uk/dv/dv08a.htm
Appendix B: Protocol Contents

• Parties to agreement
  People will need to know who the agreement is between, and will want to know that the agreement is owned at the most senior level within each organisation. It should be signed by a senior member of each agency, and the operation of the protocol should be reviewed at least annually.

• Legislation
  A brief account of relevant legislation, perhaps in the way set out in this document, may be helpful.

• Purpose
  There needs to be clarity about the overall purpose of the agreement.

• Ownership and updating
  There needs to be a clear understanding about who will take responsibility for ensuring that the agreement stays up-to-date.

• Responsibilities of parties
  It is good practice to include a short description of the role of all the parties to the agreement so that there is clarity about organisational boundaries and priorities.

• Media relations
  Looking after people with mental health problems invariably involves a degree of risk. When things go wrong, there must be a clear understanding about who will take the lead in any individual case for managing the case, including liaison with the media.

• Place of safety
  Whether this is contained within a multi-agency agreement or elsewhere, there needs to be a clear understanding between mental health services and the police about how section 136 of the Mental Health Act will be realised locally.
• **Missing patients**
  When people go missing from residential settings and there is concern about them, the police are often involved. This liaison needs to be continuous, and care needs to be taken to keep police informed of developments after the original alert.

• **Name and other changes**
  Where an individual is known to a number of agencies and key information about them changes, it is helpful to have clarity about how this can lawfully be shared across agencies.

• **Access to advice and out-of-hours arrangements**
  Statutory and voluntary organisations have much to offer each other in terms of expertise and experience, and sometimes this needs to be provided quickly. The establishment of 24-hour Single Points of Contact between mental health trusts and the police has been a particularly good example of effective practice.