

Confidentiality and information sharing

1 Introduction

This is the first in a series of briefings to assist managers of drug treatment services in developing effective management policies and procedures.

This briefing outlines definitions, good practice and current legislation with regard to confidentiality and information sharing. It covers informed consent, when confidential information can be shared and in what circumstances confidentiality can be breached. The particular issues concerning confidentiality of children and young people are not covered in this guidance as it has been prepared to improve adult drug service provision. However, the children of drug misusing parents, pregnancy and child protection issues are covered. This document provides information and general guidance only. It is not, nor is it intended to be, legal advice. It should also be read with reference to briefing number two in this series: *Data protection and record retention*.

2 Confidentiality

Confidentiality is the central trust between a service user and a drug treatment service, enabling an open and honest relationship between the service user and the drug service professional. However, information sharing is also central to providing a service user with a seamless integrated service involving other services, to best meet their needs and to reduce the risk of harm to self and others. Information needs to be shared between agencies about service users who are in contact with multiple agencies and those whose care is transferred from one agency to another. *Models of care for treatment of adult drug misusers: part two* (National Treatment Agency, 2002) sets out a national framework for the commissioning of treatment for adult drug misusers in England. It outlines the importance of information sharing to achieve seamless provision of care for the service user, providing an integrated care pathway across drug treatment providers. Drug treatment services must find a balance between the service user's right to confidentiality and the importance of information sharing. Drug service commissioners should support services to develop local protocols to achieve this balance.

No drug treatment service can offer absolute confidentiality. All service users must understand when information will be kept in confidence, when it will be shared with other services involved in their care and in what circumstances confidentiality will be breached. All drug treatment services must have a clear confidentiality policy, which is understood by both staff and service users. The policy should be presented and clearly explained to the service user, both verbally and in written form, before assessment for treatment begins. The policy should be explained on the service user's first visit to the service and the service user's understanding regularly reviewed. Service users should be explicitly advised of their rights with regard to confidentiality, including their right to access the information that is held on them.

3 Information sharing

There are a number of people who may ask a drug service for information about a service user. These include GPs, social services, the probation service, courts, employers and family/friends. It is important to have agreed policies on information sharing, which encourage effective multi-agency working within defined and clearly understood boundaries.

Data Protection Act 1998: guidance to social services (Department of Health, 2000) states that procedures for disclosure should be simple, unambiguous and specify:

- post holders who are to deal with requests for disclosure
- procedures to be followed and time limits
- safeguards to ensure that information will only be used for the purpose for which it was obtained.

Drug misusers with complex needs may have a care plan involving several relevant services and information sharing will be essential to provide a co-ordinated and seamless treatment process, an integrated care pathway. Confidential information should only be divulged with the service user's informed consent. This includes any enquiries from a partner, relative or friend of the service user.

Information can be shared for monitoring and research purposes, as long as the service user cannot be identified from the data or their explicit consent is obtained (see briefing 2 in this series: *Data protection and record retention* for more information).

If asked to provide confidential information about service users to partnership organisations, employers, friends or family, drug services should:

- seek the service user's informed consent to disclose
- anonymise data where unidentifiable data will serve the purpose
- keep disclosures to the minimum necessary. Information should be shared on a need-to-know basis
- always be prepared to justify a decision to breach confidentiality.

Once consent has been gained, it is good practice to check the identity of phone callers before giving confidential information. This can be achieved by phoning the caller back. Confidential information should only be shared in secure surroundings (e.g. where the worker cannot be overheard).

If there is a possibility that data collected anonymously for evaluation and monitoring purposes may still be attributable and used for other purposes (e.g. the police in the case of arrest referral data), this must be explicitly mentioned to the service user so that they are giving informed consent.

General principles of information sharing are outlined below:

- Information should be used only for the purposes for which it was given.
- Information about a service user should normally be shared only with the consent of that person.
- A service user may refuse to give permission to share personal information. In exceptional cases this information can be shared, if there are significant risks posed to the service user or others in not sharing this information (see section 5.1 *Breaches*).
- Information should normally only be shared on a need-to-know basis. This means only sharing the minimum information necessary to serve the best interests of the service user.
- Service users and carers should be advised why and with whom information concerning them will be shared, to enable informed consent to be obtained.
- All confidential information should be safeguarded against unauthorised disclosure (e.g. having passwords on computers that are changed regularly and procedures to check the identity of telephone callers).

- Information about service users is confidential to the agency as a whole, and not to individual workers. However, information on a service user should only be discussed with other workers in the same agency for genuine purposes (e.g. to cover work while on leave and for advice on a particular case). General discussion about a service user, which does not serve the best interest of the service user, is a breach of confidentiality.

4 Confidentiality and quality

Concerns about organisations' confidentiality practices were brought to light by the Caldicott Committee report in 1997. Owing to increasing concern about the ways in which patient information was used in the NHS in England and Wales, the Chief Medical Officer of England commissioned the Caldicott Committee to write a report on patient-identifiable information. Within the NHS, the report found that there was little awareness of requirements around confidentiality and that practice was generally poor. Awareness has improved with the introduction of new legislation and work centred around the Caldicott recommendations has begun raising standards. Each strategic health authority, special health authority, NHS trust and primary care trust should have appointed a Caldicott guardian. Ideally the guardian should be at board level and a senior health professional (e.g. the medical director). The guardian's key responsibilities are to oversee how staff use personal health information and ensure that patients' rights to confidentiality are respected. However, progress across the NHS with regard to patient confidentiality is still patchy. The Caldicott Committee report has raised the issue of confidentiality and the need to increase standards within many organisations, including the drugs field.

Treatment services should adhere to the standards on confidentiality in *Quality in alcohol and drug services: organisational standards (QuADS)* (DrugScope/Alcohol Concern, 1999). These standards are part of the nationally accepted quality standards for drug treatment services and they are recommended by government departments and the National Treatment Agency.

5 Confidentiality and the law

English common law recognises the concept of a confidential relationship and the duty of confidence. The Data Protection Act 1998 and Human Rights Act 1998 have introduced enforceable rights for service users about how the information they provide is used. The Data Protection Act has restrictions on storing personal data in all formats, written and electronic. The Human Rights Act emphasises respect for private life and strengthens the hand of those advocating increased privacy for the individual. Due to these Acts and the duty of confidentiality, there is a potential conflict between protecting the privacy and confidentiality of individuals, and protecting the public and a duty of care to the service user.

5.1 Breaches

Confidentiality can be breached:

- to protect children at risk of significant harm as defined by the Children Act 1989
- to protect the public from acts of terrorism as defined in the Prevention of Terrorism Act 1971
- as a duty to the Courts
- under the Drug Trafficking Offences Act 1986
- to prevent or detect a crime. Section 115 of the Crime and Disorder Act 1998 gives public bodies the power, but not a duty, to disclose information for the prevention or detection of crime
- to ensure the service provides a duty of care in a life-threatening situation (e.g. serious illness or injury, suicide and self-harming behaviour). This includes when a service user continues to drive against medical advice, when unfit to do so. In such circumstances relevant information should be disclosed to the medical advisor of the Driver and Vehicle Licensing Agency (DVLA) as soon as possible

- to protect the service provider in a life-threatening situation (e.g. calls to police regarding a violent service user). The Department of Health has published guidance on the issue of violence against staff, available at www.doh.gov.uk/violencetaskforce.

A decision to disclose confidential information without the consent of the service user should not be made lightly and only after consultation between the drug worker and their line manager. Every effort should be made to discuss the situation with the service user, encouraging the service user to contact the relevant authorities themselves, unless this would prejudice the outcome of any investigation or criminal proceedings. All decisions should be recorded in the service user's case notes.

There is no legal obligation to breach confidentiality in order to protect third parties or when a crime has been committed, unless and until instructed to do so by a court. However, a drug service may decide to disclose confidential information about a service user in the event of serious offences or risk to public. A drug service will need to be clear about its attitude to illegal activities and it is good practice to write this into the confidentiality policy.

Section 9 of the Police and Criminal Evidence Act 1984 allows for special treatment of information which is considered to be particularly sensitive (known as "excluded material") and this information does not need to be disclosed. This applies to material that arises in the course of a confidential, professional relationship related to an individual's physical or mental health, spiritual or welfare counselling or assistance.

6 Confidentiality and potentially violent or abusive service users

With regard to potentially violent or abusive service users, there should be no ethical objection to recording factual information about the need for particular precautions in a service user's records, care plans and other information systems. It is essential that information is transmitted effectively between organisations. The Department of Health suggests a code of practice for the exchange of information when dealing with potentially violent service users:

- Agreements in writing should be prepared between partner agencies.
- Where information about a service user is passed between agencies:
 - information should always be in writing except in an emergency, when the exact nature of the information divulged should be recorded in writing by the service as soon as possible
 - two workers should always sign such written information, one of whom should be a manager
 - the service user should always be shown or have read out such information before sending, and have the right to add their comments
 - the service user should always receive a written copy of the information passed between agencies, including the note of any verbal information
 - in the case of a dispute with the service user about the information that is being passed on, the service user should have the right to independent advocacy and an appeals system.

Exchanges of information in violent and abusive circumstances do not infringe the data protection legislation. Section 115 of the Crime and Disorder Act 1998 provides an explicit power, where none previously existed, for people to disclose information to a number of agencies if the disclosure is necessary or expedient for any of the purposes of the Act (Department of Health, 2001b).

7 Consent

Consent is an agreement to an action based on the knowledge of what the action involves and its likely consequences. To be valid, consent should be informed and freely given. The fundamental principle governing the use of information that individuals provide in confidence to drug services should be that of **explicit informed consent**, as information is likely to be of a sensitive nature (e.g. health issues), as defined by the Data Protection Act 1998. Explicit informed consent means that the service user should understand the nature and extent of the disclosure that is to be made, who is likely to receive the information and how it may be used. A general release form, which gives permission for the release of “any relevant information”, is not likely to be consistent with the principles of explicit consent. Consent does not need to be written, though a signed consent form is good practice. Informed consent does not last indefinitely. Service users can withdraw consent at any time and should periodically be given the opportunity to do so.

Where an individual is or may be incapable of making an informed decision about disclosure, the drug service must make a judgement about how to act in the service user’s best interest. Any exchange in these circumstances must be strictly according to the need-to-know principle.

8 Employment practice

All drug service staff must understand and accept the principles of confidentiality and receive appropriate training. A “duty of confidence” requirement should be included in employment contracts. This requires staff to comply with the service’s confidentiality policy and not disclose confidential information about the service, staff, volunteers, management committee and service users without permission. Staff should be aware of the possibly severe consequences of breaching confidentiality without proper authority and that they would be liable for disciplinary action.

9 Children and young people

This briefing focuses on drug treatment services for adults (i.e. those aged 18 years and over). However, adult services need to be aware of some of the issues concerning children and young people when working with pregnant service users, drug misusing parents or individuals who may commit offences against children. Drug services working with children and young people will need to reference specific children and young people literature regarding consent and confidentiality (e.g. *Young people and drugs* (Standing Conference on Drug Abuse [SCODA]/The Children’s Legal Centre, 1999)).

Under the Children Act 1989 the interest of the child is always paramount, overriding any other public interest consideration. Statutory bodies have a duty to assist local authority social services in child protection enquiries, but voluntary organisations do not. However, government guidance encourages passing confidential information, without the individual’s consent if necessary, if the child (under 18 years) is considered to be “suffering, or at risk of suffering, significant harm.”

Where there are concerns that a child or young person is “suffering from significant harm” and the drug service decides that confidentiality must be breached, consent from the individual should be sought and if possible they should be involved in the referral process. Consent should not be sought where there is a further risk of harm to the child or young adult or where this might jeopardise any subsequent investigation.

10 Specific groups

Any group that can experience prejudice and assumptions about their care may have particular concerns about confidentiality.

- Women may be worried about the social stigma that can be attached to women who misuse drugs.
- Parents may be concerned about potential social services contact and fear that their children will be taken away if they are found to be drug misusers.
- Lesbian, gay and transgendered individuals may feel that their sexuality will be told to individuals without their permission or assumptions will be made about their sexual practices.
- Black and minority ethnic individuals may be concerned that a drug service will make the assumption that they want a drug worker from their own community, though some individuals may feel more secure with someone who has no connection with their community.
- Individuals with a blood borne virus like HIV or hepatitis C may be concerned that information about their condition will be shared, affecting attitudes towards them, insurance and employment.

People from these groups have the same rights to confidentiality as anyone else. However, they may need extra reassurance about confidentiality and information sharing practices.

11 Specific settings

Drug workers are employed in multi-disciplinary teams and within different settings. Confidentiality boundaries will be service specific. Confidentiality should be explained in all service settings.

- There will be particular confidentiality issues for drug workers in prisons, where the need for security is paramount and where there is a duty to report breaches or intended breaches of prison security.
- Drug misusers involved with probation or subject to a drug treatment and testing order (DTTO) will need to give informed consent to information sharing with the probation service during the course of their order.
- Group situations (e.g. drug education and criminal justice groups) will need to set confidentiality boundaries specifically for the group, which should be included in the group ground rules.
- In low threshold services it may be appropriate to adopt a less structured approach to confidentiality in order to encourage service users to access them:
 - In outreach work, little or no assessment is likely to be carried out and it may be appropriate to maintain anonymity. In these circumstances confidentiality will not have to be explained, though it will be helpful to do so.
 - In needle exchanges, it is good practice to assess clients on their first visit, including collecting some personal and sensitive personal information, in which case confidentiality must be explained. However, assessment is not always possible - especially in community pharmacies - and should not prevent a client from obtaining sterile injecting equipment. In these circumstances it may be possible for clients to retain their anonymity, and confidentiality will not need to be explained, though it may be helpful to provide some information, perhaps in writing.

In both settings, if service users begin to disclose detailed information, the boundaries of confidentiality should be explained so that, if they continue to disclose, they are doing so with informed consent.

- Drug service professionals can be asked to attend child protection conferences to give confidential information about a service user in reference to their contact with a child. The service user does not need to give consent to this information being disclosed but consent should be gained where possible. The conference may want information about drug misuse or drug treatment, which should be provided in the interests of child protection, in accordance with local area child protection committee (ACPC) guidance. Attendance at child protection conferences should be prioritised, though a written statement is acceptable.

12 Recommended references

British Association of Counselling and Psychotherapy (2002) *Ethical framework for good practice in counselling and psychotherapy*. London: BACP.

British Association of Social Workers (2001) *The code of ethics for social work*. London: BASW. Available on www.basw.co.uk.

Department of Health (2000) *Data Protection Act 1998: guidance to social services*. London: Department of Health.

Department of Health (2001a) *Building the information core: protecting and using confidential patient information: a strategy for the NHS*. London: Department of Health.

Department of Health (2001b) *National task force on violence against social care staff: self-audit tool*. London: Department of Health.

DrugScope and Alcohol Concern (1999) *Quality in alcohol and drug services: organisational standards (QuADS)*. London: DrugScope/Alcohol Concern.

General Medical Council (GMC) (2000) *Confidentiality: protecting and providing information*. London: GMC.

Information Commissioner (IC) (1998) *Compliance advice: small business information*. London: IC. Available on www.dataprotection.gov.uk.

National Treatment Agency (NTA) (2002) *Models of care for treatment of adult drug misusers: part two*. London: NTA. Available at www.nta.nhs.uk.

Standing Conference on Drug Abuse (SCODA)/The Children's Legal Centre (CLC) (1999) *Young people and drugs*. London: CLC/SCODA.

Developing drug service policies

Briefings for managers of drug treatment services

The National Treatment Agency is publishing a series of briefings to enable the managers of drug treatment services to develop effective management policies and procedures. The briefings will provide managers with:

- a summary of key policies and related issues
- guidance on implementation.

The guidance does not constitute legal advice. Individual guidance will indicate if the NTA considers it necessary to seek legal advice.

There will be ten briefings within the *Developing drug service policies* series - all of them available at www.nta.nhs.uk.

Developing drug service policies. Briefing no. 1: Confidentiality and information sharing

Written by Julie Virgin, DrugScope.

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National Treatment Agency for Substance Misuse

National Treatment Agency
5th Floor, Hannibal House,
Elephant and Castle,
London SE1 6TE
Tel: 020 7972 2214
Fax: 020 7972 2248
Email: nta.enquiries@nta.nhs.uk
www.nta.nhs.uk



DrugScope
32-36 Loman Street,
London SE1 0EE
Tel: 020 7928 1211
Fax: 020 7928 1771
Email: enquiries@drugscope.org.uk
www.drugscope.org.uk