



Information Sharing Protocol for Multi Agency Case Management of Children with Disabilities and Extra Health Needs

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Author: Joan Debnam

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Owner	Newcastle Children's Trust Development Group:	
	Andy Roberts (Chair)	Newcastle Children's Trust
	Susan Nelson	The Newcastle Hospitals Trust
	Aileen Fitzgerald	Newcastle PCT
	Morag Hunter	Northgate and Prudhoe Trust
	Dr Sue Wressell	Newcastle North Tyneside and Northumberland Mental Health Trust
	Jean Langley	Newcastle Local Education Authority
	Pat Thompson	Newcastle City Council, Social Services
	Ed Jones	Fame Project Team
	Joan Debnam	Fame Project Team
	Roger Vaughan	Newcastle University
	Ann Cassidy	North Tyneside Council
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Author	Joan Debnam	

Reviewers

Reviewers	Role
Graeme Farrow	Acting Information Governance Strategy Manager. Northumberland, Tyne & Wear Strategic Health Authority
Rachael Shimmin	Head of Commissioning /Caldicott Guardian Newcastle City Council
David Gunn	Data Protection Officer Newcastle City Council
Caroline Winter	Solicitor Newcastle City Council
Dr Michael Laker	Caldicott Guardian The Newcastle Hospitals NHS Trust
Vida Morris	Caldicott Guardian Newcastle PCT
Dr Andrew Fairbairn	Caldicott Guardian Newcastle, North Tyneside & Northumberland Mental Health Trust
Dr Anthony Perini	Caldicott Guardian Northgate & Prudhoe Trust

Revision History

Revision Date	Version	Reason for Change
16/04/04	0.01	Draft for comments
27/04/04	1.00	Amendments following review
28/04/04	1.01	Delete “de-personalised” Change to “anonymised” following review by Newcastle City Council Legal Section
13/05/04	2.00	Section 6.5 added following review by Andy Roberts
14/06/04	3.00	Incorporating suggestions from Graeme Farrow
18/06/04	3.01	Minor typing adjustment to job title

Review Arrangements

1. The first formal review will be six months after date of implementation.
2. Reviews will then be annually unless legislative changes, organisational restructuring or breach of the Data Protection Act by any of the partners require more immediate action.

1 Introduction

This protocol covers statutory and professional responsibilities and follows national policies and guidelines and legal requirements concerning the sharing of information where this involves sharing personal information across the FAME pilot project

The partners to this agreement are those agencies and teams that will participate in the Newcastle FAME pilot project (**F**ramework for **M**ulti Agency **E**nvironments)

1.1 Background to the FAME Project

The FAME project is an e-government project funded by the Office of the Deputy Prime Minister. FAME will develop a framework for multi-agency information sharing that will help improve provision of more efficient, effective and holistic services. For further details visit the FAME website www.fame-uk.org The Newcastle strand of the project will develop an electronic case management system for children* referred to the pilot services. This system will support the aim of Newcastle Children's Trust to provide a single process for referral, assessment, care planning and review of children with disabilities and extra health needs.

2 Purpose

The Green Paper "Every Child Matters" sets out the Governments long term vision to integrate the commissioning and delivery of services to children and families. Information sharing is crucial to enable multi agency services to develop joint working practice to improve outcomes for children and their families and develop effective, user focused, integrated services. This protocol provides the assurances that the public should expect about the appropriate and safe use of personal information and the purposes of anonymised data drawn from it.

Within the FAME pilot the focus will be on sharing information leading to:

- Less frustration for families by not having to repeat information already given
- Bringing information together from a range of professionals involved with the child to provide a more collaborative response to meet children's needs
- Provide a mechanism for children and parents* to contribute to the shared information and to access information held on them
- Development of a single assessment process and shared case management system
- A source of information which will be drawn on for purposes of needs analysis, supply analysis and strategic planning of services and resources. Information used for these purposes will be anonymised so that no individual can be identified.

**Throughout the document children means children or young person
and parent means parent or those with parental responsibility*

3 Principles

Each organisation subject to this protocol shall identify a nominated representative with sufficient authority to implement and oversee the operation of the protocol.

Personal information will only be exchanged when “need to know” requirements are met i.e. access to information is required for staff to fulfil their function at that particular time and with the informed consent of either a child who has sufficient understanding to give their own consent or their parent. When sharing or disclosing personal information for the purposes described in section 2, partners to this protocol will adhere to the following principles:

1. Ensure that personal information is dealt with legally, securely, efficiently and effectively in order to provide the best possible outcomes for the child.
2. Ensure that the best practice principles detailed in appendix two are met.
3. Ensure that staff are provided with the necessary training to be aware of and comply with their responsibilities in both the confidentiality of information and with the commitment to share.
4. Audit the handling of information to identify any discrepancies against standards and take corrective steps if indicated.
5. Review organisational procedures that support the management and operation of this protocol and put in place any updates/improvements as indicated.

4 Key Legislation

The following legislation regulates the exchange of information between the partners subscribing to this protocol:

- Children Act 1989
- Education Act 1996
- The Education Act 2002
- National Health Service and Community Care Act 1990
- Health Act 1999
- Local Government Act 1972
- Local Government Act 2000
- Crime and Disorder Act 1998
- Data Protection Act 1998
- Freedom of Information Act 2000
- Human Rights Act 2000

For further guidance on lawful information sharing and best practice, see appendices 1 and 2

5 Partner Organisations and Teams

The Newcastle Hospitals Trust

Community Paediatrics
Children's Community Nursing
Specialist School Health Nursing
Paediatric Therapy (Physiotherapy & Occupational Therapy)
Speech Therapy

Northgate and Prudhoe Trust

Community Team for Learning Disability

Newcastle North Tyneside and Northumberland Mental Health Trust

Child and Adolescent Mental Health Service

Newcastle Primary Care Trust

Loan Equipment Service

Newcastle City Council

Children with Disabilities Social Work Team
Welfare Rights
Short Break Service
Special Educational Needs Teaching and Support Service (SENTASS)
Educational Psychology
Schools as selected

The Local Authority will process data on behalf the partner organisations

5.1 Specific Roles of Pilot Teams

Referrals arise from primary care, acute services and generic services and will initiate a single service/team assessment or a multidisciplinary assessment depending on which service or combinations of services/teams are referred to. Loan Equipment for example will only deal with the referrals for equipment, while services which have a role in assessing the child's needs will work collaboratively. Shared information/documentation will be made available to staff who provide care and/or treatment, so that collaborative approaches to assessment, care plans and review are enabled.

6 Information to be shared and the basis for sharing

Data will be processed in accordance with the principles of the Data Protection Act (DPA). Personal information will only be with the explicit consent of the child or their parent.

6.1 Information held in existing systems

The FAME project will aim to access and combine information held by the IT systems of the participating services. Initially basic details of children who are known to have multidisciplinary involvement will be used to populate the Fame system. It is anticipated that initial downloads will be taken from Newcastle City Council Education and Social Services information systems. The basic details are: full name, gender, address, date of birth, GP, school attended, date of school annual review (if applicable) pupil/client identifier and names of workers involved.

There will be an exercise to inform data subjects of this change and to provide opt out for those not wishing data to be transferred.

When a referral is made to one or more of the pilot teams basic details will be added if a record does not already exist

6.2 Common Referral Form

Referrals are made when the referrer identifies a need which they believe can be met by the service or team to which the referral is made. For children with multiple or complex needs this can entail referral to more than one service or team. The Fame project will develop an electronic referral form which has a common component and additional components depending on the speciality referred to. Services or teams will be notified that the child has also been referred to others within the project. A closed community consisting of workers with direct involvement, their managers and necessary admin staff will have access to referral information depending upon their authentication level.

6.3 Joint Assessment, Plan of Intervention and Review

When the situation arises where a child is referred to more than one service or team within the Fame project the system will flag this up. This alert prompts those involved to have a discussion and nominate a lead professional. The lead professional's name is recorded on the system. The lead professional will take on the role of coordinator to oversee the assessment and review process. Specialist assessments will contribute to an overall assessment. The overall assessment, plan and review will be recorded on the system using shared documentation.

6.4 Information for monitoring, service planning and statistical returns

Data from which no individual can be identified will be used for local monitoring and service planning and statistical returns to central government.

6.5 Information on services that may be of benefit to children and their families

Newcastle Children's Trust and its partnership organisations may want to draw on the data held in FAME to contact families about Health, Social Care or Educational services which may be of benefit to them. When an individual states that they do not wish details of their name and address used for this purpose. This will be respected and a note held in the consent field not to be contacted by mail shot.

7 How compliance will be assured.

7.1 The organisations represented by the Children's Trust Developmental Group have overall responsibility for compliance with this protocol. The nominated representative of each organisation is responsible for ensuring that local procedures are in place for the:

- Formal approval and adoption of this protocol
- Dissemination/circulation of the protocol
- Confirmation of adopting standard procedures
- Monitoring and reviewing procedures

7.2 In common with other information sharing issues Caldicott Principles will apply and will be monitored within Agencies existing Caldicott review systems.

7.3 Individual staff have responsibility to ensure that they adhere to the principles.

7.4 The Children's Trust Development Group will work with their organisation to ensure that the procedures necessary to support this protocol are in place. These are:

- Providing information to individuals, at first contact, describing the proposed uses of the collected information.
- Obtaining parents and/or child's (if child has capacity to consent) to referral and information sharing within the closed community of the FAME pilot.
- Recording consent to share information for the purposes of joint assessment of children and families referred to more than one service/team within the Fame pilot.
- Defining circumstances when information may be disclosed without consent.
- Provide training to staff in the operation of this protocol and their legal responsibilities for personal information.
- Authorise information exchanges and review them initially after six months then at least annually
- Define levels of access and need to know basis.
- Agree security standards based on risk assessments.
- Provide an audit trail to identify those who have or attempted to access specific records.

- Procedure for notification of unauthorised access attempts.
- Procedure for correcting factual inaccuracies in person identifiable information.
- Develop procedure for electronic and non electronic parental/child access.
- Develop dissemination plan for the protocol.
- Develop a retention policy for shared records.
- Develop a complaints policy to address complaints and objections about the operation of this protocol.
- Formally Review the protocol.

8 Access and security

All users of the FAME system will be allocated a “user profile” based on their role and function in relation to the provision of care/services of the child. User access rights support the principle of access to information on a strict need to know basis e.g. profile for Senior Manager, Team Manager, worker or essential admin staff.

All users will have an individual user id and password which they must keep private.

User rights will be documented by each organisation and be kept up to date. This will log who has access, which profile they have, when access began and when (if necessary) it will cease.

Access rights for each worker will be identified by a Senior Manager

In the event of access by a professional without a predefined relationship to the child a flag will warn that the system is monitored and instruct the user to justify the reason for accessing the record. This access will be notified to the Children’s Trust Manager.

8.1 Access by third party

The system administrator will be granted access to provide a “help line” facility to support staff using the system. Any requests to correct errors will be handled by the system administrator.

The company supplying the software will be granted access to allow them to fix defects, update software etc. The supplier must maintain the confidentiality of any information they see whilst performing these tasks.

9 Declaration

The partners to this protocol accept that the procedures laid down in this document provide a secure framework for the sharing, disclosing or joint use of personal data between their agencies in a manner compliant with their statutory and professional responsibilities. As such they undertake to implement and adhere to the procedures and structures set out in this Protocol.

9.1 Signatures

We the undersigned agree to adopt and adhere to this Protocol:

Signature	Name	Position	Organisation	Date

Appendix 1: Existing Legal Framework

In deciding whether the proposed sharing of information is lawful the following questions should be considered:-

- A. Have we the power to carry out the function to which the proposed information sharing relates?
- B. Does information sharing comply with the Human Rights Act, particularly Article 8 of the European Convention on Human Rights?
- C. Does the proposed information sharing comply with common law of confidentiality?
- D. Have the principles under the Data Protection Act 1998 been complied with?

Legal Powers (Summarised)

Public Bodies e.g. local authorities derive their powers from statute and must not act outside these statutory functions. A well established principle in law is that that the actions of public bodies are authorised by the interpretation of these powers. This principle is reflected in section 111(1) of the Local Government Act 1972

“Local Authorities are expressly empowered to do anything which is calculated to facilitate, or is conducive or incidental to, the discharge of any of their functions”

In current legislation there is no general statutory power to share information. Therefore the legal basis for sharing information must be based on the function to which the information sharing is ancillary to. The key legislation which supports sharing personal information for the purposes described in this protocol is listed in section 4. Further details of this legislation can be found on the Department of Constitutional Affairs website

<http://www.dca.gov.uk/foi/sharing/toolkit/lawguide.htm>

Appendix 2: Best Practice Principles

Caldicott Principles

The Caldicott report places an obligation on NHS organisations and Local Authorities to ensure that personal information will only be shared or disclosed where the purpose can be justified and that personal information will be kept to a minimum. Requests for personal information should be assessed against six Caldicott Principles:

- 1) Justify the purpose for which the data is sought.
- 2) Only use personal information where it is absolutely necessary.
- 3) Use the minimum necessary personal information.
- 4) Access to personal information should be on a strict “need to know” basis.
- 5) Ensure that everyone with access to personal information is aware of their responsibilities in relation to it.
- 6) Users of personal information must understand and comply with the law.

Where information does not support the provision of care information should be anonymised in accordance with Caldicott principles.

Duty of Confidentiality

Information is considered to have been provided in confidence when it appears reasonable to assume that the provider of the information believed that this would be the case. Partners in this protocol accept this duty of confidentiality and shall not disclose such information without the consent of person concerned, unless there are exceptional circumstances.

Exceptional Circumstances

Exceptional circumstances in which an individual's right may be overridden would be where information is required by statute or court order, where there is serious risk to public health, risk of harm to self or others or for the prevention, detection or prosecution of crime.

Consent

Explicit or Express Consent means an articulated agreement. The terms are interchangeable and relate to a clear and voluntary indication of preference or choice, usually given orally or in writing and freely given in circumstances where the available options and the consequences have been made clear.

Implied consent means that agreement has been signalled by the behaviour of an informed individual.

Seeking consent may be difficult if circumstances have prevented individuals becoming informed about the likely uses of their information or if they have difficulty communicating their decision. Efforts must be made to ensure that information is provided in suitable formats or language that is accessible.

Competency to Consent

Young people aged 16 or over are presumed to be competent for the purposes of consent to treatment and are therefore entitled to the same duty of confidentiality as adults. Children under the age of 16 who have the capacity and understanding to take decisions are entitled to make decisions about the use and disclosure of information. This is a complex issue and there are circumstances when a child's wishes may be overridden by those with parental responsibility. Parents and Professionals working together are best placed to encourage and include children in decision making.

When consent is sought from those with parental responsibility it is important to check that such a person has proper authority. Ideally any special circumstances about parental responsibility should be held on the child's record under additional information.

Fair Processing

Informed consent is a guiding principle in the use of personal data. When information is collected details of how the information will be used and shared will be provided. The express consent of the individual should be sought, recorded and complied with, unless there are overriding reasons to disclose without consent.

It is unnecessary to seek specific consent each time information needs to be passed on for a purpose defined within this protocol, provided that individuals have been fully informed of the uses to which their information may be used.

Where an individual states that they do not want their personal information disclosed or used for specific purposes their wish will be respected unless there are exceptional circumstances. The consequences of withholding information for care or planning must be explained, but the decision rests with them.

Responsibilities of Staff

All staff have an obligation to safeguard the confidentiality of personal information. This is governed by statute, and professional codes of conduct. Partners to this protocol should ensure that staff are provided with the necessary training to be aware of, and comply with their responsibilities in regard to confidentiality of information and the commitment of their organisation to share information to improve outcomes for children.

Organisational Procedures

Existing organisational procedures, such as Induction, Training, Recording, Confidentiality, Appraisal and Supervision, are available to support staff in meeting their responsibilities to this protocol.

Breaches of compliance to this protocol will be dealt with by the appropriate procedures of their employing organisation.

Complaints

Partners to this protocol will develop procedures to address complaints and concerns raised by members of the public or staff concerning the operation of this protocol.