Leeds Partnerships NHS
NHS Foundation Trust

Information Sharing Agreement

between

Leeds Partnerships NHS Foundation Trust

and

Leeds Child and Adolescent Mental Health Service (CAMHS)

Date effective from:	3rd March 2011
Review date:	3rd March 2013
Version number:	1.0

See Document Summary Sheet for full details

Leeds Partnerships NHS
NHS Foundation Trust

DOCUMENT SUMMARY SHEET

ALL sections of this form must be completed.

Document title:	Information Sharing Agreement between LPFT & Leeds Child and Adolescent Mental Health Service (CAMHS)
Document reference number:	ISA-0002
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Document author (Title)**:**	LPFT: Information & Knowledge Manager CAMHS: Information Governance Manager
Document author (Name)**:**	LPFT: Carl Starbuck CAMHS: David Green
Ratified by:	LPFT: Medical Director & Caldicott Guardian CAMHS Head of Service
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DOCUMENT AMENDMENT SHEET

Please record what changes you have made to the procedural document since the last version.

This is a detailed tracked change document and is designed to show people exactly what has changed. The version number recorded below should correspond to the ratified version number shown on the Document Summary Sheet.

Version	Amendment	Reason
0.1	N/A	First draft for consultation
0.2	Various minor changes	Second draft for agreement – amended by CAMHS IG lead.
0.3	Minor changes	Proof-read & final check for ratification. Minor changes only by LPFT IG lead.
0.4	Minor changes	Additional content added to “purposes” section by CAMHS IG lead.
1.0	Ratified	Signed off by both parties

1. Introduction

This agreement is written to promote the sharing of personal data and / or sensitive personal data, as defined by the Data Protection Act (1998). It is developed under the umbrella of the Pan-Leeds Inter-Agency Information Sharing Protocol (2008). It describes the information which will be shared between the partner organisations and arrangements for assisting compliance with relevant legislation and guidance, including the Data Protection Act (1998).

Information sharing agreements do not in themselves make the sharing of personal data and / or sensitive personal data legal or ethical. The Data Protection Act (1998) sets out the context in which information may be used legally, with this agreement and the over-arching protocol echoing the legislative framework and promoting best practice and co-operation across partner organisations.

The following statement should guide all information sharing within the Information Sharing Partnership:

Whenever there is a need to share personal data and / or sensitive personal data, the specific reasons for sharing the information should be recorded, along with why it is considered relevant. The volume and detail of information shared must always be sufficient but not excessive for the required purpose. Wherever possible, decisions to share information should be made within the context of appropriate support, rather than by staff acting alone.

Where information is fully anonymised, or is otherwise non-identifiable or wholly statistical in nature it is not necessary to apply this agreement. Care must be taken however to establish that information is fully anonymised, as the obvious fields of person-identifiable data may not be the only positive identifiers within shared material.

2. Background

Leeds Partnerships NHS Foundation Trust and Leeds Child and Adolescent Mental Health Service (CAMHS) have agreed to share personal data and / or sensitive personal data for the purposes listed in section 3. The background to this is to allow the transition team to work at the interface of the two services to support a planned, orderly process of transition from CAMHS to Adult Mental Health services.

On October 1st 2010 Leeds CAMHS moved their upper age limit from the 17th to the 18th birthday for service users. This presented an opportunity to improve the transition process between services and two transition posts were created in CAMHS. The purpose of this transition team is to work at the interface of the two services to support a planned, orderly process of transition from CAMHS to Adult Mental Health Services (AMHS).

Research[1] has shown that without a supported transition young people are at risk of dropping out of treatment to the detriment of their future mental health.

In line with current best practice guidelines[2] Senior Managers from both services and Aspire, have drawn up a protocol[3] for transfer of service users between child and adult services.

In order to evaluate the effectiveness of these changes, the transition team need to track referrals moving from CAMHS to AMHS and to monitor the outcomes of referrals.

The following information, if made available to the transition workers, would enable transition to be evaluated in a way that will inform the practice of both child and adult mental health services:

- Was the referral accepted or declined by AMHS?
    - If accepted, by which part of the service?
    - If declined, what was the reason for this?
    - If declined, was the young person signposted to a different service?

The answers to this group of questions will enable CAMHS clinicians to be informed as to the eligibility criteria and the threshold of clinical need, for referrals to be accepted by the Adult service. This should improve efficiency, as fewer inappropriate referrals would be made. It would also cut down the need for service users to be redirected to a more suitable service.

- Has the young person attended a first appointment? (Yes, did not attend, no appointment yet offered.)
- Did the young person attend a different service? (Yes, no, not known)
- Is this still an open case? (yes, no)
- If discharged, how long was the young person in the service?

These questions would inform the services about how far it has been possible to engage the young person in the new service. This will provide information as to the effectiveness of improving engagement by means of the transition process which seeks to involve service users in decision making about their own care, to provide the same link worker for continuity as they move from one service to another, and to promote a period of joint or parallel working with clinicians from both child and adult services.

3. Purposes for sharing

Information Sharing Purposes
• To monitor the outcome of referrals made by the Leeds CAMHS to Adult Mental Health Services, for a small number of young people who, on reaching the age of 18 years, are still in need of support for their mental health

difficulties.
- To support a planned, orderly process of transition from CAMHS to Adult Mental Health Services.
- To monitor the effectiveness of the protocol for transfer of service users between child and adult services.

4. Legal basis for sharing

A clear legal basis is required for sharing personal information about service users. The Data Protection Act (1998) and common law requirements provide the framework under which personal information can be used, held, and disclosed. In general terms the main basis for sharing would be one of the following:

1. In order to provide healthcare for the service user
2. Consent of the service user has been obtained where their information is being used for non-healthcare purposes or where a disclosure is being considered that the service user has not anticipated
3. A statute of law obliges the agency to release the information
4. Sharing without consent e.g. where there is an overriding public interest in sharing such as the prevention of harm to the service user or other individual, prevention of a serious crime.

The purpose that personal information is being shared between the children's and adult service relates to the provision of healthcare. This is a legitimate purpose for the processing of personal health data as outlined in condition 8 (Medical Purposes) from schedule 3 of the Data Protection Act.

The service user in being referred to the adult service will anticipate that some information will need to be shared between the old and new service in order to ensure that their healthcare programme is continued. There will also be the expectation that services regularly monitor healthcare processes in order to implement improvements where necessary. This expectation of patients will be supplemented by staff explaining verbally and/or through distribution of organisational leaflets informing service users of the use of their information (including sharing with other agencies). This will meet the fair processing (ensuring service users are aware on how their information is used) element of the Data Protection Act.

5. Type of information that will be shared

In respect of this agreement, the following types of information will be shared:

- Was the referral accepted or declined by AMHS?
- If accepted, by which part of the service?
- If declined, what was the reason for this?
- If declined, was the young person signposted to a different service?
- Has the young person attended a first appointment?

(Yes, did not attend no appointment yet offered.)

- Did the young person attend a different service?

(Yes, no, not known)

- Is this still an open case?

(Yes, no)

- If discharged, how long was the young person in the service?

6. Methods Used for Sharing Information

Information may be shared in the following ways:

- Information accessed in situ, via provision of access to organisational databases or records.
- In written information transferred by secure e-mail.
- In written communications transferred by fax.
- Documents transferred on CD, DVD or other electronic digital media.
- In written communications, (for example, alert / referral forms, letters, statements or reports) transferred in hard copy through internal or external mail services.
- Verbally i.e. face to face, in wider meetings or on the telephone.

When any of these methods is used it is essential to consider the security in the access, processing and recording of information, and to ensure safe transit and delivery. Information should be appropriately secured in transit, transferred by methods aligned to the best practice specified in the Data Handling Procedures in Government: Final Report – June 2008.

Verbal conversations and interviews should be recorded in a statement that is agreed by the information giver. Care must be taken to record and denote information clearly as fact, statement or opinion and to attribute any statement or opinion to the owner. All information should be recorded in such a way that it can be used as evidence in court, should that be required at a later date.

Meetings should be recorded in minutes that are agreed by the delegates present.

Written communications containing confidential information should be transferred in a sealed envelope and addressed by name to the designated person within each organisation. They should be clearly marked "Private & Confidential".

When files are transferred on CD, DVD or other electronic digital media, the files should be encrypted to an appropriate standard, with decryption keys / passwords supplied separately.

When confidential information is sent by e-mail, it should be sent and received using secure government domain e-mail addresses, to ensure encryption of information in transit. Secure e-mails include the following e-mail address domains:

- NHS (*.NHS.net)

- GSi (*.gsi.gov.uk)
- CJX (*.police.uk or .pnn.police.uk)
- GSE (*.gse.gov.uk)
- GSX (*.gsx.gov.uk)
- GCSX (*.gcsx.gov.uk)
- SCN (*scn.gov.uk)
- CJSM (*cjsm.net)
- MoD (*.mod.uk)

In-transit security is reliant on BOTH the sender AND recipient using one of the e-mail domains listed above. In the absence of this, the SENDER will need to encrypt the content of the e-mail using additional software. This may be achieved by sending an encrypted attachment. Encryption software may be purchased or obtained from public domain sources for this purpose (e.g. WinZip, TrueCrypt etc), whilst document-level encryption is supported in business application suites such as Microsoft Office.

Encryption standards are set out in NHS Connecting for Health guidance on the following link:

Connecting for Health – Encryption Guidance

When confidential information is sent by fax, it should be sent to a 'safe haven' fax. This is a fax machine that is managed in such a way that you can be confident that information can be transferred to it in the knowledge that safeguards are in place to ensure its security and that access is restricted to assure confidentiality.

In all transfer scenarios, the onus is on the SENDER to ensure that:

- Information is transferred securely
- The chosen method is acceptable to and workable by the recipient
- Information has reached the required recipient

In the event that a recipient receives information by an unsecured route, it is incumbent on the recipient to advise the sender and agree a secure route for future transfers of information.

7. The Need To Know

A prime consideration of access to or sharing of information is the 'Need To Know'.

Although access to information may be possible within the remit of a role, or access granted to systems on which information is stored, this does not necessarily mean that any individual should access information stored therein, or that they should access information beyond that which is necessary to perform a given task. This is best expressed as follows:

- Access to information should be on a strictly 'Need To Know' basis.

- Records must only be accessed when there is a clear 'legitimate relationship' between those accessing the records and the subject of the records.

Within a legitimate relationship, the level of records access should be limited to that information which is relevant to task.

8. Consent from Individuals to Share their Personal Information

Staff and volunteers should always seek consent from individuals before sharing their personal data and / or sensitive personal data, whenever possible and appropriate. They should record the consent, when given, on their organisation's standard consent documentation, or as a contemporaneous entry into the electronic records system.

Where it is not possible to obtain consent, this could be because:

- the individual does not have the mental capacity to consent
- it may not be safe to seek consent
- it may not be possible to seek consent for some other reason

In cases where it has not been possible to seek or obtain consent, staff or volunteers should always record the justification for sharing the information, and how this decision was arrived at.

1. If the individual does not have the mental capacity to consent, staff or volunteers should record this using their agency's Mental Capacity Assessment recording tool or other appropriate method, and record their decisions to share information using their agency's Best Interests Decision recording tool or other appropriate method.

2. If the subject has not given consent for reasons other than those covered by the Mental Capacity Act, one of the reasons from Schedule 2 of the Data Protection Act (1998) is required to justify the sharing of personal data, whilst a reason from Schedule 2 AND Schedule 3 is required to share sensitive personal data. Those reasons with particular relevance to this agreement are included below:

Schedule 2 – Justifications for the sharing of personal data:

- Compliance with the legal obligations of partner organisations
- Protecting the vital interests of the subject
- Carrying out tasks or duties substantially in the wider public interest
- Pursuing the legitimate interests of the partner organisation

Schedule 3 – Justifications for the sharing of sensitive personal data:

- Compliance with employment law obligations
- Protecting the vital interests of the subject

- Legal advice and establishing or defending legal rights
- Public functions (including the administration of justice)
- Medical purposes and the provision of healthcare
- Detection of unlawful activity
- Protection of the public
- Confidential counselling
- Police processing

For further advice on justifiable grounds for sharing information, contact your organisation's Data Protection specialist or Caldicott Guardian. If your organisation does not have such a role, your line manager may be able to advise you on the most appropriate source of guidance.

9. Information Retention and Disposal

The Data Protection Act (1998) requires that personal data and sensitive personal data is not retained for longer than necessary. Partner organisations may have their own organisational, legal or procedural requirements for records retention and disposal. These retention schedules should be observed and applied at all times.

Where no such organisational procedure exists, it is essential to keep pertinent information as long as there continues to be a need, and equally that such information is securely disposed of when no longer required.

10. Dissemination & Training

Each partner organisation should develop their own approach to dissemination of this agreement and the provision of awareness and training to support its use.

11. Access Agreements

Where information is to be shared via granting inter-organisational access to systems operated by partner organisations, the 'owning' organisation of the system will draft and agree an Access Agreement with the partner organisation to govern the activities of partner staff using the system.

A template for this purpose can be found in the Pan-Leeds Inter-Agency Information Sharing Protocol.

12. Discipline

Although this agreement seeks to promote the sharing of information between partner organisations, use of the information shared should never exceed the purposes or intentions of the original reason for sharing.

Where allegations are made that information has been used inappropriately, or that the confidentiality of subjects has been breached, partner organisations will co-operate in a full and frank investigation of these allegations.

In the event that any wilful misconduct is substantiated which resulted in a breach of subject confidentiality, this will be regarded as an act of serious or gross misconduct and actioned accordingly.

Instances of inappropriate access to electronic records may be regarded as criminal action under Section 1 of the Computer Misuse Act (1990), and may result in a custodial sentence. (r vs Dale Trever, 2010).

Sharing partners should maintain an awareness of current relevant legislation.

13. Performance of this Agreement

Should any member of staff or volunteer working for a partner organisation feel that the letter and spirit of this agreement is not being honoured, or that barriers to legitimate sharing of information are being raised, this should be communicated to their organisation's Information Sharing or Information Governance lead, who will in turn follow this up with their counterparts in the partnership organisation(s).

14. Supporting Documentation

Pan-Leeds Inter-Agency Information Sharing Protocol 2008, and supporting documentation.

ICO Framework Code of Practice for Sharing Personal Information

Data Handling Procedures in Government: Final Report – June 2008

NHS Confidentiality Code of Practice – November 2003

Appendix A

Proposal for Information Sharing between the Child and Adolescent Mental Health Service and the Adult Mental Health Service.

This paper is offered in support of a request for information on the outcome of referrals made by the Leeds CAMHS to AMHS, for a small number of young people who, on reaching the age of 18 years, are still in need of support for their mental health difficulties.

On October 1st 2010 Leeds CAMHS moved their upper age limit from the 17th to the 18th birthday for service users. This presented an opportunity to improve the transition process between services and two transition posts were created in CAMHS. The purpose of this transition team is to work at the interface of the two services to support a planned, orderly process of transition from CAMHS to Adult Mental Health services.

Research[1] has shown that without a supported transition young people are at risk of dropping out of treatment to the detriment of their future mental health.

In line with current best practice guidelines[2] Senior Managers from both services and Aspire, have drawn up a protocol[3] for transfer of service users between child and adult services.

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Finally auditing referrals on a regular basis will highlight problems such as referrals not being received or recorded fully and allow the opportunity for both services to improve the efficiency of their practice.

Janet Shepherd
Senior CAMHS Practitioner
Transition Team

08/12/10

[1] **Transition from CAMHS to Adult Mental Health Services (TRACK): A Study of Service Organisation, Policies, Process and User and Carer Perspectives**

Report for the National Institute for Health Research Service Delivery and Organisation programme
January 2010

prepared by
Professor Swaran P Singh
Health Sciences Research Institute, University of Warwick et al

[2] **The National Service Framework for Children, Young People and Maternity Services (Department of Health and Department for Education and Skills, 2004)**

Core Standard 4: 'Growing up into Adulthood'.

This standard emphasises multi-agency transition planning, benefits of joint working between AMHS and CAMHS, involving young people and families in decision making, and improving service users' autonomy.

[3] **Services Transfer Protocol**

Between: Child and Adolescent Mental Health Services
And: Adult Mental Health Services

See Appendix B

Appendix B

Services Transfer Protocol

Between: Child and Adolescent Mental Health Services
And: Adult Mental Health Services

Introduction:

This protocol deals with the interface between child & adolescent (CAMHS) and adult mental health services in Leeds. The document provides guidance concerning the appropriate service to which young people should be referred at different points in their care and gives information on agreed transfer procedures for young people who need to be transferred from the care of CAMHS to adult services.

This protocol is underpinned by the service policies and principles of both Child and Adolescent Mental Health Services and Adult Mental Health Services and by the policies and procedures of the Care Programme Approach.

1 Age transition points for referral/allocation to child and adult services

Young people referred to mental health services in Leeds will be the responsibility of the child & adolescent mental health service up to their 18th birthday. If a young person is nearing his/her 18th birthday discussions need to take place between CAMHS and AMHS to agree the most appropriate way forward for the individual concerned. If the individual is likely to require ongoing treatment the referral may be better placed within the adult services. Where there is reason to suspect that the young person (14-34yr) has a psychotic disorder a referral to the Aspire Early Intervention in Psychosis team would be more appropriate. The Aspire team will act as Care Co-ordinator and will liaise with other services (including CAMHS or adult services) accordingly.

Where a first episode of psychosis has been identified, the Aspire team will provide care co-ordination for a period of 3 years. With the exception of medical cover, the full use of the resources within the aspire service are available to this client group. Medical responsibility will remain within the CAMHS service prior to the 18th birthday, at which point it will transfer to the aspire consultant. This will be coordinated by the care coordinator via a CPA meeting and process. Aspire will, in turn, arrange transfer for cases requiring adult mental health services after 3 years. This will be facilitated by the CPA process.

2 Transfer from CAMHS to AMHS

Most young people will not need to be transferred to adult mental health services. CAMHS will continue to see a service user after their 18th birthday for a limited period if the service user does not meet the criteria for transfer set out below. Even if they do, it may be appropriate for CAMHS to continue care beyond their 18th birthday if it is anticipated that the episode of care can be concluded within a few months.

2.1 Criteria for transferring a young person to adult mental health services

- A diagnosis or ongoing symptoms of psychosis or equivalent severe and enduring mental illness.
- A need for continued monitoring of psychotropic medication
- Mental health/psychological needs that are likely to continue into adulthood and to require the expertise and resources of specialist adult mental health services.

It is important to point out to young people that they can themselves seek a referral to AMHS via their GP – if they have not been transferred to AMHS via this protocol.

2.2 Planning for transfer

- Young people aged up to 18yr and over who may need transfer will be prospectively identified by CAMHS
- Where possible, planning should start 6 months before probable transfer date
- The **young person** (and where appropriate their family) will be at the **centre** of the process, and involved at all stages. Information should be given to the young person regarding the transition to adult service.
- Advocacy for the young person should be arranged as appropriate.
- The principles of local CPA arrangements will be followed as set out in the Trusts procedures on the care programme approach. “CAMHS staff will need awareness of the key points of LPFT procedures on the implementation of the CPA.
- Where a young person is acutely unwell, the transfer should generally be postponed until the service user’s mental state has improved.

2.3 Initial Contact with Adult Services

- Initial contact should be made by telephone between the CAMHS case holder and the identified Adult CMHT Clinical Team Manager in the local sector team. The Adult Clinical Team Manager will identify the receiving named Care Co-ordinator.

2.4 Transfer/referral Letter

- The formal transfer/referral should be made by letter to the person identified, CTM and sector Consultant. The letter will include the information included in Appendix 1, and date of the CPA transfer meeting.

2.5 Professional Meeting/Discussion

- The CAMHS case worker is responsible for making contact with the identified named receiving Adult Care co-ordinator and facilitating the most appropriate

method of transfer which will include a full transfer of appropriate documentation, history, care plan and risk assessment.

2.6 The CAMHS case worker will arrange a joint CPA meeting which should involve the young person (family as appropriate) to discuss the situation and plan the transfer of care. This CPA meeting should be attended by all those involved in the young person's care and may include:

- The Adult Services Care Co-ordinator
- The CAMHS case worker
- Advocacy
- Other relevant professionals where appropriate
- Transition process, including planned date
- Any joint working/transition needed
- Agreement on roles and responsibilities
- Timescales/dates for transition

Where there is likely to be problem with engagement, a clear plan should be drawn up according to the young person's needs as to how this can be addressed.

Where equivalent services are less readily available (e.g. family therapy), consideration should be given to a 'staggered' transfer or a period of shared care.

The CAMHS caseworker will provide the young person with appropriate information about their transfer of care to the adult services.

2.7 The CPA meeting will be documented by the CAMHS case worker and forwarded to the adult Care co-ordinator and copied to the young person.

2.8 At the end of the transfer CPA process a discharge letter will be produced by the CAMHS case holder and circulated to all involved, including the service user's General Practitioner. As per appendix 1.

2.9 At the first CPA meeting a follow up CPA will be booked within a 6 month period and the CAMHS previous case holder will be invited to attend.

2.10 If agreement cannot be reached for an individual young person on any aspect of this transfer process then a professionals meeting should be called to attempt to resolve any disagreements.

3 Requests for Crisis assessment and admission to an Adult mental health bed for a patient currently with CAMHS (not under 18 yrs)

If a young person post 18yrs is still under the care of CAMHS and requires hospital admission the CHRTT must be involved in the assessment to determine if alternatives to hospital admission can be considered eg CRHTT/Home Treatment or Acute Community Services. If alternatives to hospital admission are not considered appropriate, the CRHTT will arrange for the patient to be admitted into one of the adult inpatient wards.

During the period of hospital admission the patient will be the responsibility of the adult inpatient psychiatrist. CAMHS should continue with their involvement during the admission to ensure good in reach to the ward and timely discharge. CAMHS will continue to work with the patient post discharge and consider transfer to adult community care at an appropriate time post acute crisis. Discharge may be facilitated via CRHTT/home based treatment or Acute Community Services with CAMHS continuing in the role as community case worker. If a patient is being treated in CRHTT/Home Based Treatment medical responsibility will be with the CRHTT Consultant Psychiatrist, if the patient is placed in ACS the medical responsibility will sit with the CAMHS Consultant Psychiatrist (as per the adult service model) – if a CAMHS psychiatrist is currently allocated to that person. If not, then an adult psychiatrist will be allocated.

4 Request for assessment following self-harm

If during a period of CAMHS care post 18 years, a young person presents at A&E following a self-harm episode the LPFT DSH Team will make assessment and recommendation about further treatment and care. The outcome of the assessment should be made available to the CAMHS team and case worker at the earliest opportunity. If admission is considered the pathway outlined in 3 above will be followed.

5 Monitoring the implementation of this protocol

This protocol will be monitored through the CAMHS and will monitor the following three areas:

- The number of young people successfully transferred between CAMHS and AMHS
- The number of young people where a transfer is requested by a CAMHS but not accepted by AMHS
- The number of 18 year olds active to the CAMHS at any one time.

6 Making young people aware of other adult mental health services in the city

For those young people who are likely to require mental health services in the future but do not currently meet the criteria for AMHS, it is important for CAHMS to provide them with information about other services such as IAPT or non statutory services which they can access.

Janice Morris
Clinical Services Manager
15/09/10

Appendix B(i): Information required in transfer letter

Identification data:
Name, Address
Date of Birth
NHS Number & GP details

Initial Presentation including:
Referral source
Initial presentation
Initial formulation with primary and subsidiary diagnoses

Family/Carers including:
Family/carers structure
Assessment of family/carer dynamics if relevant
Family history of mental health problems

Current circumstances including:
Behavioural, mental health symptoms, social functioning
Accommodation
School (counselling, school attendance, statement)
Communication
Offending behaviour/history
Substance misuse
Learning difficulties (and educational attainment)
Spiritual and Cultural needs
Independent living skills
CPA level of need

Interventions including:
Details of current care plan
Duration
Effectiveness
Names and contact details of other agency workers involved

Risk including:
Suicide & Self Harm
Violence/Aggression
Neglect
Child protection issues

Physical Issues

Developmental History

Rationale for referral including:
Present symptomatology and formulation
Remaining difficulties
Ongoing requirements for therapy
Medication

13. Signatories to the Agreement

Approved by: Dr Douglas Fraser – Medical Director & Caldicott Guardian

For: Leeds Partnerships NHS Foundation Trust

Date: 03.03.2011

Dr Douglas Fraser

Approved by: Mark Swindells – Head of Service

For: Child and Adolescent Mental Health Services, NHS Leeds Community Healthcare

Date: 24.02.2011

M. Swindells

A copy should be sent to the Data Protection Officer / Caldicott Guardian of each partner organisation for approval and signature. In the absence of the above roles an appropriate senior signatory will suffice.

Copies of this Agreement should be retained by the named persons above and be made available for inspection.