NHS
Connecting for Health

Child and Adolescent Mental Health – General Care Record Action Team

Final Report

Version 3.0

Date 12.06.06

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Amendment History:

Version	Date	Amendment History
1.0	24.05.06	Initial Draft
2.0	30.05.06	Amendments made
3.0	12.06.06	Amendments made- MW&JB

Forecast Changes:

Anticipated Change	When

Reviewers:

This document must be reviewed by the following. Indicate any delegation for sign off.

Name	Signature	Title / Responsibility	Date	Version
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Approvals:

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CAMHS Care Record Action Team

CAMHS Care Record Extended Reference Group

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Related Documents:

These documents will provide additional information.

Ref no	Doc Reference Number	Title	Version
1	NPFIT-SHR-QMS-PRP-0015	Glossary of Terms Consolidated.doc	6

*Glossary of Terms***:**

List any new terms created in this document. Mail the NPO Quality Manager to have these included in the master glossary above [1].

Term	Acronym	Definition
National CAMHS Support Service	NCSS	Organization to support service development and implementation of national policy agreements across Child and Adolescent Mental Health services. Part of the Care Services Improvement Partnership (CSIP) http://www.csip.org.uk
CAMHS Outcome Research Consortium	CORC	Collaboration between Child and Adolescent Mental Health Services to implement a common model of outcome evaluation and to aggregate and analyze the data centrally in order to provide meaningful information to service providers and other stakeholders, including service users. Currently about half of all CAMH services across the UK are members http://www.camhoutcomeresearch.org.uk
National CAMHS Dataset	NCDS	Dataset for CAMHS developed on the basis of widespread service provider consultation and consistent with mapping requirements and the NHS data dictionary available via http://www.camhoutcomeresearch.org.uk

Children and Young People Group in National Institute of Mental Health-England	CYP group in NIMHE	Network of people working in a variety of capacities (both in statutory and voluntary sectors) to support the development and improvement of Child and Adolescent Mental Health Services. www.camhs.org.uk Convened by the Fellow in Child Mental Health for the National Institute of Mental Health- England, part of the Care Services Improvement Partnership (CSIP) http://www.csip.org.uk
FOCUS	FOCUS	Network of CAMH professionals functioning largely via email discussion forum open to all professionals working in CAMHS http://www.rcpsych.ac.uk/crtu/focus.aspx
Child and Adolescent Mental Health Services Evidence Based Practice Unit	CAMHS EBPU	Part of the Department of Psychology at University College London. The unit aims to research, promote and disseminate evidence based practice in relation to Child Mental Health service practice and development.
Mental Health Partnership-CAMHS Subgroup	MH Partnership-CAMHS Subgroup	Collaboration of MH Trusts across the UK with the aim of supporting each other in developing best practice across their services. Sub-group focused on CAMH services.
CAMHS Mapping	CAMHS Mapping	Annual mapping of service activity across CAMHS across England co-ordinated via Durham University. Involves Service Leads completing an annual questionnaire. Results available via the CAMHS mapping website. www.dur.ac.uk/**camhs.mapping**

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1.

ACTION TEAM: Child and Adolescent Mental Health – General Care Record[1]
ACTION TEAM LEAD: Miranda Wolpert
PROJECT MANAGER: Jonathan Bureau
LOCATION OF ACTION TEAM: *CAMHS Evidence Based Practice Unit, Anna Freud Centre, London*
SHA LEAD: Bob Foster
ACTION TEAM START DATE: 1st December 2006
DATE OF FINAL REPORT: 31st May 2006
1. BACKGROUND
The collection and availability of robust data for every stage of a child or young person's progress through child and adolescent mental health services (CAMHS) is a pre-requisite for the creation of accurate and relevant records of care and for the provision of a high-quality service. Such data enable services to both properly manage individual children (including ensuring child protection issues are adequately addressed), and to monitor activity, performance and outcomes on an ongoing basis. There are 139 specialist CAMHS providers across England. The majority of these are health providers but increasing numbers are being developed as collaborations between health, social care and education (e.g. through the establishment of Children's Trusts). The development of a care record for CAMHS therefore has to be meaningful and relevant within this multi-agency service delivery environment. In 2002 a process of widespread consultation with service providers was initiated which lead to the development of the basis for a care record for CAMHS called the "National CAMHS Dataset (NCDS) (Appendix 9). This was published in 2004 and represented best practice to date. It was widely disseminated to all services via the National CAMHS Support Service and has been widely taken up (Appendix 11). It was developed to be compliant with other existing datasets and the NHS data dictionary as well as linking with the

[1] *Please note, Karen Tingay's input into this project as part of the core team, is contributing to her ongoing PhD "An innovative approach to child and adolescent mental health care records with relevance to routine outcome evaluation" (unpublished Doctoral thesis, UCL) and therefore it is important to explicitly recognise her invaluable contribution to this project in particular in relation to her audit of NICE guidelines and their implications for care record development; her collation of the suggested refinements to the national CAMHS dataset and her suggestions about how these might be operationalised.*

Department for Education and Skills (DfES) defined data items.

The CAMHS Outcome Research Consortium (CORC) is a UK-wide collaboration between CAMH services is to develop and implement a model of routine outcome evaluation, to aggregate the data centrally and to analyse and disseminate the results in such a way as to provide meaningful information to both service providers and users (Appendix 13). Membership of the consortium has continued to grow during the life of the DOAS project from 40+ members at its inception to over 70 CAMHS across the UK - over half of all services.

As CORC relies on members using consistent data sets, CORC has agreed to oversee the refinement of the data for a CAMHS care record based on "The National CAMHS Dataset" and to update the dataset in the light of emerging practice in line with emerging National Programme for Information Technology (NPFIT), Children/CAMHS policy, DfES dataset developments (such as the Information Sharing Index) and other initiatives.

CORC is therefore committed to disseminating any agreed proposals for a care record that emerges out of this Do Once and Share project, whether it is based on the NCDS or not. However, given that the NCDS was itself the product of extensive consultation, review of its merits and demerits alongside those of any other datasets, and proposed ways forward, will be crucial.

The DOAS links with other concurrent initiatives. The Health and Social Care Information Centre (HSCIC) has just embarked on planning for the development of a secondary purposes dataset for CAMHS, in close collaboration with the CAMHS policy group in the DH/DfES. Also, Connecting for Health London and their LSP are looking to implement an agreed care record for CAMHS. The leads of both initiatives have welcomed this DOAS as an initiative that will dovetail very productively with these areas of work and act as a source of practitioner based advice and as a powerful catalyst to ensure systems that are developed really do meet clinical and other needs on the ground.

PROJECT OBJECTIVES

- Build on work already done nationally through CORC and specifically in identified CAMHS services (those that have implemented a care record in a variety of different service structures) to analyse issues in relation to implementation, suggest agreed key elements of a care record system and make suggestions as to the implications for the development of a secondary uses dataset.

- Working with practitioner and service managers experienced in service needs, data collection, and analysis, to define a set of key fields for the

management of children’s mental health services. This data set needs to be robust, take into account local variability in patterns of care and service provision, is sustainable in an interagency context, and serves the needs of practitioners, managers, and service planners.

- Examine and recommend ways of linking together all relevant information sources and processes relevant to CAMHS and identify future work that needs to be done. This is to be achieved through, securing local and national ‘stakeholder’ engagement to ensure both sustainability and a credible, informed body of practitioners to help support the ongoing development of the NHS’s Information Management and Technology infrastructure.

- Identify models by which the data can be used to feedback to the practitioner to help improve outcomes (both in terms of outcome and outputs).

SHA EXECUTIVE SUMMARY

Name: Bob Foster

This project is a vital one for the CAMHS community, as practitioners struggle to understand and appropriately influence the development of a care record and related IT developments to support CAMHS provision in an increasingly multi-agency environment.

The project has managed to engage a wide range of CAMHS stakeholders in relation to this task and to facilitate discussion and debate of the issues raised, to increase awareness of the range of possibilities and to identify best practice to date in this complex area. It has been able to support policy developments regarding secondary data and now provides a clear way forward for NHS organisations seeking to improve their information systems on children’s mental health

The team has worked hard (and successfully) to link with emerging national policy and developments across different departments and agencies, and has managed to pull together a clear consensus as to the way forward that can best help inform these developments both now and for the future.

4. DETAILED REPORT ON WORK WITHIN SCOPE (any outputs from this work which are not covered as specific deliverables)

Output 1: Links made with other allied dataset developments

Status: Completed- but with continuing systems in place to ensure appropriate ongoing stakeholder involvement

Date of Completion: 31 May 2006

Summary of findings:
Links have been made with the following key projects and groups in the following ways:

- Child and Maternity Information Board (Chair; Mark Davies, DH)-– Miranda Wolpert, a member- to continue after project ends
- CAMH Information Group (Chair; Cathy James, DfES) . Miranda Wolpert a member- to continue after project ends
- CAMHS-messaging work (Lead; Kevin John, Gavin McIntosh) input via Miranda Wolpert, Samuel Stein and Bob Foster- now complete but wider links to stakeholder community established (Appendix 21)
- Pan-Cluster group (Chair: Hugh Griffiths/ Gavin McIntosh) - Chris Scarborough (member of DOAS extended reference group) now invited to join group to represent CAMHS (Appendix 6)- to continue after project ends
- HSCIC CAMHS minimum dataset development reference group : Ashley Wyatt (member of DOAS extended reference group and CORC vice-chair) nominated as member to represent DOAS- care record experience and CORC expertise to continue after project ends
- Joint statement drawn up on how key dataset developments linked together and widely circulated (appendix 12)
- Key people involved in dataset developments invited to present at National Stakeholder event (appendix 22)

Appendixes:
6 Minutes of extended reference group Jan-May 06
12 linking developments
21 Key areas of CAMH data to be held on spine
22 national stakeholder event papers

Output 2: Stakeholder engagement

Status: Complete- but continuing action proposed

Date of Completion: 31 May 2006

Summary of findings:

- Stakeholder engagement has progressed via key stakeholder networks and communities across CAMH including communication and consultation via the MH Partnership, the CYP group in NIMHE, FOCUS an via CAMHS Mapping networks. (Appendix 17)
- Overall it is estimated that at least 3,000 CAMHS stakeholders were consulted via email and other networks (this is likely to be a conservative estimate- larger numbers were circulated but this allows for overlap between circulation methods but does not allow for numbers to whom the information was forwarded). This suggests that of the estimated 8,000 CAMH workforce and other stakeholders a significant number will have had an opportunity to comment on and contribute to this work. Over 100 people from over 60 organisations actively contributed either via email or by their contribution at national or other group events (Appendix 17)
- Meetings of Reference Group (Appendix 6)
- National event held 4th May 2006 and all presentations made available via web (appendix 22)
- Web presence created via NCSS site (www.camhs.org.uk) as well as via Connecting for Health.

Future plans- for key stakeholders involved in various dataset development groups to stay connected via CAMHS EBPU and for networks established to remain in email contact co-ordinated via CAMHS EBPU (Appendix 6)

Appendices:
6 Minutes of extended reference group Jan-May 06
15 Communications summary
22 national stakeholder event papers

UPDATE ON PROJECT CONSTRAINTS and RISKS

The project manager was only recruited to project a month into project and working part time to cover both this and the CAMHS-LD DOAS - risk was that it would not be possible to manage workload in time available

It was difficult to decide how best to engage user perspective in relation to care record elements as there was concern that asking service users to comment on technical issues could be simply tokenistic.

There was a very real risk of confusion between overlapping dataset developments.

There was a risk that members of the Core and Reference groups would not have sufficient access to information to make informed comments on the diverse developments in the NHS and other agencies, particularly those that impact directly and indirectly on the specification of the care record and the dataset. In particular, lack of access to relevant developments such as SNOMED CT were considered a risk. On the other hand there was also a risk of becoming bogged down in technical details when the aim was to bring practitioner perspective.

There was the risk of trying to take on too much in such a large and complex scope area.

6. DETAILS OF ANY CONTINGENCIES IMPLEMENTED

The Project manager worked hard with support provided via other team members; and in particular with invaluable support provided by Annie McIntosh from CfH centrally [NB please see comment from Clinical Lead at end].

The team members ultimately agreed that consultation with user groups would be via consultation on key aspects of care record rather than on technical details. For example consultation is being carried out via CORC to identify what outcome-focused measures service users would like instituted and recorded. (Though CORC will not report on this in time for the end of this project, findings will be fed into relevant dataset development groups via membership listed above)

Great efforts were made to keep in regular communication both written and over the phone with other dataset developments and agreed common understandings in writing wherever possible

Effort was placed in précising technical information wherever possible and disseminating it in most digestible forms possible e.g. via briefing paper

The central team tried to keep a balance between appreciation of systems and focus on clinical issues in all meetings, and referred back to scope where in doubt.

The team checked wherever possible for areas of commonality with other DOAS and have agreed to leave those areas more appropriately dealt with elsewhere e.g. issues of consent or final decisions about how to code some aspects of child protection referred to work of relevant DOAS groups (David Low)

Deliverable name: Define the nature of the data required in relation to CAMHS.

Status: Complete

Date for Completion: 31 May 2006

Summary findings:

- Consultation with extended reference group and others has identified key components necessary for a care record (Appendix 6 and 8)

- Consultation with extended reference group and others suggests the NCDS is most widespread comprehensive care record system for CAMHS currently in use, it has been used by several independent database developers to create databases for services who report it meets their needs well (Appendices 6, 7, 11).

- The NCDS has been reviewed to see what needs need amendment in relation to selected areas and a list of refinements drawn up and consulted on (Appendix 10);

- Very preliminary and brief (and tentative) review of SNOMED to identify gaps (Appendix 6)

Appendices:
6 Minutes of extended reference group Jan-May 2006
7 Mapping exercise summary
18 Clarification of OBS
10 suggested refinements to NCDS
11 report on uptake of NCDS

Deliverable name: Advice to the national programme (and thus LSPs) on the suitability of the current system specification as it applies to young people with mental health issues.

Status: Complete

Date for Completion: 31 May 2006

Summary findings: Advice to this effect has been developed (Appendix 18)

Appendix:
18 clarification of OBS

Deliverable name: Create an engaged and informed CAMHS practitioner

community who can aid the further development in this field.

Status: Complete- but with ongoing activity

Date of Completion: 31 May 2006

Summary of findings:

- Stakeholder engagement has progressed via a number of routes including communication and consultation via the Mental Health Partnership, CYP group in NIMHE, FOCUS etc and supported by a briefing paper designed to spell out key issues and encourage comment and input (Appendices 8 & 15)
- National event held in May 2006 – well attended (Appendix 15) and attendees agreed to be used as email consultation group for relevant documents and developments
- Clear consensus from stakeholders on key issues (Appendix 20)
- Web presence created via NCSS site (www.camhs.org.uk) as well as via CfH site
- Continuing network of involved CAMHS stakeholders to be co-ordinated via CAMHS EBPU
- Key documents (eg tools and rules form for national library) circulated to network
- Network alerted to key events eg e-prescribing consultation events

Appendices:
6 minutes of extended reference group Jan-May 2006
8 Briefing paper
15 Communications summary
20 Key issues identified by stakeholders may 2006

Deliverable name: Feedback on developments to the relevant Royal Colleges and professional societies via the membership of the CYP Group.

Status: Completed

Date for Completion: 22nd May 2006

Summary findings:

- DOAS presented at CYP group in NIMHE initially in December 2005 and then finally on 22nd May 2006 (Appendix 19).

Appendix:
19 ppt presention to CYP group re DOAS May 2006

Deliverable name: Review of current datasets in use in the CAMHS field and evaluate strengths and weaknesses and possible identification of national way forward.

Status: Completed

Date for Completion: 31 May 2006

Summary of findings:
Following widespread consultation with CAMHS providers on care records they are using currently (Appendices 7 & 15); exploration of strengths and weaknesses of existing systems (Appendices 10 & 16) and review by the core team and extended reference group (6), core components of any dataset for CAMHS have been identified and widely consulted on (Appendix 10, 18) and a proposed refined dataset (based on an amended version of the National CAMHS Dataset) has been suggested (Appendix 10) .

Appendices:
6 Service provider extended reference group minutes Jan-May 2006
7 Mapping exercise summary
10 final refinements to NCDS
15 Communications summary
17 NICE /guideline audit
18 Clarifications of OBS

Deliverable name: Identification of training needs.

Status: Completed

Date for Completion: 31 May 2006

Summary findings:

- An initial task that was identified as a priority was finding a common language with stakeholders as to what is mean by a care record and the systems that support it and how this might be of benefit and relevance to their work…a briefing paper to help in relation to this

was developed and disseminated (Appendix 8) . This was well received and we had much positive stakeholder comment on having the issues spelled out in this way

- It was clear from the feedback that many practitioners struggle with the use of technical language used in relation to IT development and possibilities of future developments in this regard are identified below (see section 8 below on possible future initiatives)

Appendix:
8 Briefing paper

Deliverable name: A clear statement of the benefits of a system fit for purpose.

Status: completed

Date for Completion: 31 May 2006

Summary findings:

- The briefing paper and web developments are designed to deliver on this and have been made widely available to CAMH stakeholders
- The dissemination of key materials from CfH such as the tools and rules questionnaire and request for involvement in developing messaging workshops and e-prescribing have also been part of this process

Appendices:
8 Briefing paper

Deliverable name: Progress reports as required in the terms of reference, including recommendations on the areas that require further work at the conclusion of the project.

Status: completed

Date for Completion: 31 May 2006

Summary findings:

- Progress reports delivered on schedule

- Requirement for future work so far identified and passed on to CfH centrally include the following suggestions for further work in relation to :a) transition issues (between child and adult services and between agencies) b) looking at a particular topic area where there is NICE guidance (suggestion; Child Depression to look at issues in relation to CPA for children, supporting NICE guidance in terms of decision making supports and information requirements generally and transition issue between child and adult services).

8. ADDITIONAL INFORMATION

Continuing work arising out of this project:

It is anticipated the NCDS will now be revised in the light of the DOAS and made freely available to all CAMH stakeholders and others

Training materials are still being developed to help inform the CAMH community about the advantages and benefits of use of data to inform service development e.g. the revised version of the CORC handbook currently in development will be made freely available to all CAMH stakeholders

The network of interested CAMH practitioners brought together by this project will continue to be facilitated via the CAMHS EBPU in order to allow continued input and consultation on relevant dataset developments

A web presence established on the NCSS website will be maintained to inform CAMH stakeholders of the relevant issues arising out of ongoing projects

9 CLINICAL LEAD ADDITIONAL COMMENTS

There has been a high level of interest and involvement from CAMHS practitioners in this project despite the difficulties with the technical aspects of this area. This has been, fuelled, in particular, by the common wish for genuinely joined up systems across health, education and social care to be created in such a way as to maximally benefit children and families. This project has, however, highlighted the fact that this join up can only happen if government departments lead the way in agreeing joined up solutions and the issues highlighted by this project need to be addressed if child safety and benefit is to be ensured (see appendix 20).

A strong and engaged network of stakeholders has developed as result of this project and the CAMHS EBPU will continue to facilitate the co-ordination of this group and access to it by any relevant dataset and other development initiatives in order to disseminate key information and to try to ensure that CAMH-specific issues are considered and incorporated as part of wider developments.

This project has been able to function due to the hard work (often over and above employed hours) put in by so many colleagues. I want to particularly

thank Jonathan Bureau for his role as project manager, and to also Annie McIntosh who provided such invaluable support and guidance throughout. I also want to acknowledge the input of all the members of the core team, extended reference group and allied colleague who have put in such dedicated work to help form a consensus as to the best way forward.
12. Do Once and Share PROGRAMME COMMENTS (Programme Manager or KPS Director)

SIGN OFF

SHA Lead	**Bob Foster**
Name:	
Signature:	
Date:	**31 May 2006**
DOAS Programme Manager	
Name:	
Signature:	
Date:	
KPS Programme Director:	
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Date:	