Minutes of the meeting of the Sub Committee of the Confidentiality Advisory Group

February 2016

Reviewers:

Name	Capacity	Items
Dr Mark Taylor	Chair	All
Ms Kim Kingan		All
Mr Patrick Coyle		All
Dr Murat Soncul		All

NEW AMENDMENTS

1. **CAG 2-03 (a)/2013 - Application for transfer of data from the Health and Social Care Information Centre (HSCIC) to commissioning organisation Accredited Safe Havens (ASH) – Amendment request (data controllers)**

This amendment set out a change to data controllers and a change to data processors. It stated that following the decision to cease further development of Accredited Safe Havens by the Department of Health, it would be necessary to bring the initial arrangements for Stage 1 ASHs in line with the future solution, whereby Commissioning Support Units only operate as data processors on behalf of their commissioner data controllers.

Request background

The context provided confirmed that previously the HSCIC entered into Data Sharing Agreements (DSAs) with CSUs on behalf of Clinical Commissioning Groups (CCG). It stated the HSCIC has revised their policy and can now only enter into a DSA with data controllers. This means that the current DSA arrangements will need to transfer from CSUs to CCGs directly. Currently, the data release of data from DSCRO to Stage 1 ASH under the existing support is based on two key criteria:

i. IG Toolkit compliance to at least level 2
ii. DSA between the Stage 1 ASH and HSCIC to be in place.

The amendment confirmed that CSUs will no longer be able to meet criteria (ii) as a result of the changed HSCIC policy. The proposal was for CSUs to operate as data processors on behalf of CCGs and maintain their Stage 1 ASH accreditation, by virtual of their IG Toolkit compliance, and a contract with CCGs, underpinned by an overarching NHS England agreement with HSCIC providing oversight for CSUs.

NHS England therefore requested the following amendment detail of the following Stage 1 ASH criteria for CSUs to be:

i. IG Toolkit compliance to at least level 2

ii. DSA between the Data controller and HSCIC to be in place for data to be released from HSCIC to DSCRO
iii. Data processing contract to be in place between the data controller and CSU providing Stage 1 ASH services
iv. CSU status as Stage 1 ASH is conditional to their NHS Status.

Justification for change:

The amendment highlighted the following:

- NHS England retains management oversight for CSUs and would like to maintain their status as Stage 1 ASH, so that de-identified data containing a single identifier is controlled in a limited number of accredited places; rather than all CCGs.

- CSUs would only have access to de-identified data containing a single identifier for CCGs where they have a service and data processing contract in place.

- The transition of DSAs from CSUs to CCGs will occur over a period of time, the current arrangement remains in place until such time the new DSAs are in place between HSCIC and CCGs,

- The change in HSCIC policy is in line with the future state solution, where CSUs will only operate as data processors on behalf of their commissioning customers.

Confidentiality Advisory Group advice

The Confidentiality Advisory Group was unable to provide a recommendation via the sub-committee due to the issues raised, and recommended that responses to the clarification requests should be considered and presented back to the next available meeting.

Clarification for submission to full CAG meeting.

1. Members noted that support was due to expire 30 March 2016 although a formal duration amendment had not been submitted. The applicant was advised to submit a formal amendment accordingly should the intention be to request continuation of support.

As a whole, the sub-committee group felt that the amendment raised a number of profound issues but the amendment itself was relatively brief in terms of implications, and there were some errors that made the content difficult to understand.

2. Members questioned whether this was a long-term arrangement now intending to replace the original details of the ‘interim solution’ application on a permanent basis, and noted that any change to data controller arrangements would entail a new application, if approved, to accurately reflect revised arrangements.
3. Provision of clear data flow diagrams detailing a) the current flow of data and b) the flows proposed following this amendment; please define the data sets and advise who the Data Controller and Data processors are in each state. It should be clear how the flows proposed under (b) relate to the future solution.
4. Provision of a timeline for the changes including a) the present state, b) the state following this amendment and c) the proposed future solution.
5. It was questioned whether those CCGs that are currently ASHs will lose their status.
6. What assurance is there that CSUs have the capacity to undertake this work and they have sufficient staff ably trained in information governance to ensure the confidentiality of patient data.

7. The understanding was that the HSCIC will only have DSAs with data controllers and CCGS (not CSUs), however it was unclear how the data would flow. As the CCG will not be an ASH, it was unclear whether they could receive a dataset with one identifier – the presumption was not – and confirmation was sought on whether this identifier would have to flow directly to the CSU ASH and the CCG will only receive de-identified data processed by the CSU?
8. Have private/third party organisations been used to process data in the past and is it planned to use such organisations in the future?
9. Is there a further plan that ultimately there will only be one ASH i.e. HSCIC itself?
10. Provide clarity on what is meant by 'overarching NHS England agreement with HSCIC providing oversight for CSUs' to clarify the oversight arrangements.

Responses would be considered at the next available CAG meeting, when submitted.

2. CAG 2-03 (a)/2013 - Application for transfer of data from the Health and Social Care Information Centre (HSCIC) to commissioning organisation Accredited Safe Havens (ASH) – Amendment request (identifiers)

Request background

The original approved application had specified that the disclosure from HSCIC / DSCROs to Stage 1 ASHs would consist of de-identified data with a single identifier e.g. NHS Number or postcode. The applicants had specified originally that concurrent disclosure of data sets with separate identifiers would be enabled through providing the CAG with a business case. The amendment specified that the HSCIC had not approved subsequent requests for concurrent disclosure, in the absence of a business case submitted to the CAG in line with the details of the original application. This amendment sought to address this issue on a more general basis, rather than the original proposal.

Justification for change:

The amendment asserted that as Stage 1 ASHs had been in place for 18 months that it had become increasingly apparent that there is a need for individual Stage 1 ASHs to have access to data sets, so that the same organisation (CSU or CCG) can undertake different analyses with the separate data sets. The data sets are not intended to be linked together as they are used for separate purposes, with controls to prevent cross linkage between the different data sets. Typically NHS number is used for most commissioning purposes to support patient pathway analysis and contract monitoring of specific purposes. Postcode is used as a unique identifiable to support service analysis where geographic detail is needed e.g. service flows, travel time for service re-configuration.

The amendment specified the justification for change as follows: concurrent release of data sets with separate single identifiers will be controlled by appropriate data sharing agreements that will specify the controls necessary and state the purpose for each data set, including controls to maintain separation of the data sets.

Confidentiality Advisory Group advice

The Confidentiality Advisory Group was unable to provide a recommendation via the sub-committee due to the issues raised, and recommended that responses to the clarification requests should be considered and presented back to the next available meeting.

Clarification for submission to full CAG meeting.

1. Clarification as to how this aligned with the previous amendment of change to data controllers/processors.
2. Provision of both NHS Number and postcode was considered to be a significant step from the detail previously approved as it was moving away from the concept of 'de-identified data for limited access'. The brief reassurance provided regarding no intention to link the datasets did not provide sufficient confidence that there will be a robust system in place to guarantee that requests will be justified.
3. Members expressed concern at the lack of consistent identifiers being used
4. Further information to be provided on the technical and managerial aspects that will be consistently used to prevent inappropriate linkages.
5. Concern was expressed at the brief arrangements specified in terms of NHS England reviewing and agreeing the purpose for which a dataset is requested, as it was felt to be ambiguous and potentially open-ended.
6. Clarification as to how the proposal fits into the end-state previously described.

Responses would be considered at the next available CAG meeting, when submitted.

3. CAG 2-03 (a)/2013 - Application for transfer of data from the Health and Social Care Information Centre (HSCIC) to commissioning organisation Accredited Safe Havens (ASH) – Amendment request (data set inclusion)

Amendment request 1 - mental health

In the CAG 2-03(a)/2013 submission, the commissioning data set requested included Mental Health Data. The submission did not specifically mention the Mental Health Minimum Data set (MHMDS) and Mental Health Learning Disability (MHLDDS) data sets that are collected by HSCIC. As such mental health data sets have not been disclosed by the HSCIC to DSCROs for use. Since the original application, further work on mental health data standards has progressed towards a consolidated standard.

The HSCIC would like assurance that there is a clear legal basis for the Mental Health data sets held by HSCIC (MHMDS and MHLDDS) and, in the future, the updated Mental Health Services Data Sets (MHSDS) to flow to DSCROs. The DSCROs would provide a service for de-identification and linkage to other commissioning data sets as part of their data management process and make available either a dataset with one identifier (de-identified data for limited access) to Stage 1 ASH organisations, or fully pseudonymised to CCGs. The additional datasets were confirmed as follows:

- Mental Health Minimum Data set (MHMDS)
- Mental Health Learning Disabilities Data set (MHLDDS)

- Mental Health Service Data set (MHSDS) (once available)

This amendment was stated to be a necessary mechanism to reduce local flows of mental health data to support the transition towards the 'future state' solution.

Additionally, improving mental health was stated to be a key area of focus for CCGs, and to do that they needed to understand what services are being accessed to better plan and make sure sufficient capacity is available, and that the services being utilised meet the contractual requirements.

Amendment request 2 - maternity

Since the CAG 2-03(a)/2013 submission, it was stated that the HSCIC has been working on a programme to collect Maternity Services Data Set (MSDS) to improve monitoring of maternity services. The data has been collected from providers since April 2015, and since June 2015 approximately 70% of providers have been submitting the data set to the HSCIC.

The amendment requested support for NHS the HSCIC to make this data set available to DSCROs for de-identification and linkage to other commissioning data sets and make this available to Commissioners (CCGs and NHS England) to support improvements to maternity services.

NHS England would like to request an amendment to application to include Maternity Services Data Set (MSDS) in the commissioning data sets covered by the current s251 support.

Confidentiality Advisory Group advice

Members noted that DSCROs were currently part of the HSCIC and the intent was for these to receive a dataset with one identifier (following the concept of de-identified data for limited access,' specified in Dame Fiona Caldicott's report).

It was also noted that mental health data was included in the application, but not specifically MHMDS. Members recollected that the original advice on support was based on the assumption that this would be a short-term solution while a more robust long-term solution was worked through. In assessing the sensitivity of the dataset, members balanced the proposition that, if this data is required to provide better mental health services, to fail to provide the data to those planning services could be viewed as discrimination against those with mental health problems.

While supportive in principle of the amendment, Members concluded that appropriate patient notification materials were of prime importance, combined with the ability of patients to be informed and to provide an objection if they choose, particularly if there are any concerns about any mental health issues becoming more widely known.

It was noted that the availability of the privacy notice by the HSCIC was not submitted and when searched for, appeared to make minimal mention of right of patient objection with non-helpful language. Specific to the existing data flows, it was also noted that those receiving the data would have patient notification materials but as this is an application by NHS England on behalf of individual organisations, the CAG would not have sight of these.

It was agreed that the importance of appropriate patient notification applied also to the amendment for inclusion of the maternity dataset

Specific conditions of support:

1. Applicant to provide clear information to provide assurance that relevant patient information materials are very easily available with information on how to object. This should be provided within 20 working days.

2. Confirmation as to how NHS England will ensure there are easily available, appropriate patient notification materials, for all those who will receive data under this support

4. **CAG 7-07 (a-c)/2013 Invoice Validation supporting the provision of healthcare to supplement data used within application CAG 2-03(a)/2013: Application for transfer of data from the Health and Social Care Information Centre (HSCIC) to commissioning organisation Accredited Safe Havens (ASH)**

Amendment request

The amendment made by NHS England to enable the disclosure of de-identified data using a single identifier from a Stage 1 ASH to a controlled Environment for Finance (CEfE) for invoice validation purposes provided the following context to support the amendment.

For smaller providers such as walk-in centres for emergency services, there is benefit for the provider and the commissioner for a lead commissioner to pay for the total activity at the provider and for payment to be cross-charged to the appropriate CCG by allocating activity, and for the lead CCG to generate an NHS to NHS invoice for payment by the originating CCG.

Operationally, local activity data for the service such as a walk in centre is sent by the provider to the DSCRO, this is then de-identified and made available for reconciliation by the Lead CCG (or their appointed CSU) within a Stage 1 ASH. The Lead CCG would then generate individual invoices to each originating CCG as a cross charge for their patient activity.

In order to make the process more manageable, the amendment requested a change so that for this purpose of invoice validation, de-identified activity data containing a single identifier can be sent from the Stage 1 ASH to the receiving Controlled Environment for Finance (CEfF) (specified within the original application) together with the invoice for the cross charge. This will enable the receiving CCG to confirm that the invoice is for the correct patient(s) and facilitate approval of the invoice for payment.

Justification of amendment

The purpose of the request is to allow NHS England to assess the need and appropriateness for this flow in the future and to allow CCGs and NHS England to re-procure the services requiring the provider to invoice the appropriate provider. Enabling the Lead CCG to be invoiced for all activity is a method to minimise the administrative burden and financial risk for small providers (e.g.GP practices or cooperatives) It was confirmed that releases of activity details will only be shared with approved CEfF, and that this release does not increase the data being shared with the Lead commissioner.

The amendment stated that the inability to share activity data from Stage 1 ASH to CEfE means that there are a number of invoices that have not been paid, or have not been checked prior to payment. The purpose of the request is therefore to allow NHS England to assess the need and appropriateness for

this flow in the future and to allow CCGs and NHS England to re-procure the services requiring the provider to invoice the appropriate provider.

NHS England would like to request an amendment to the Stage 1 ASH arrangements and supporting s251 approval to include disclosure of de-identified data using a single identifier from a Stage 1 ASH to a CEfE for invoice validation purposes. This will enable the receiving CCG to confirm that the invoice is for the correct patient(s) and facilitate faster payment approval of invoices.

Confidentiality Advisory Group advice

Members agreed that this appeared to be a reasonable request that would reduce burden on smaller providers. The sub-committee concluded that suitable justification had been made to demonstrate a public interest in this amendment proceeding, and therefore agreed to recommend to the Secretary of State for Health that the amendment be approved. All other standard and specific conditions of support remain applicable for CAG 7-07 (a)/2013.