

Data Access Advisory Group (DAAG)

Minutes of meeting held 25 August 2015

Members: Alan Hassey (Chair), Eve Sariyannidou, John Craven, Patrick Coyle, Dawn Foster, James Wilson, Joanne Bailey (item 3)

In attendance: Victoria Williams, Stuart Richardson, Garry Coleman, Dave Cronin, Paula Moss, Julia King, Rob Shaw (part), Estelle Spence, Julie Shippen

Apologies: Sean Kirwan,

1	<p>Review of previous minutes and actions</p> <p>The minutes of the 18 August 2015 meeting were reviewed and a minor typo was amended on page 2. The minutes were agreed as an accurate record.</p> <p>Action updates were provided (see table on page 6).</p> <p>The Chair welcomed Dr James Wilson to his first meeting of DAAG.</p> <p>Out of committee recommendations</p> <ul style="list-style-type: none">• NIC-315716 Imperial College London
2	<p>Data Applications</p> <p>NHS East and North Hertfordshire CCG – ASH (Presenter: Stuart Richardson) NIC-371050-X4H9L</p> <p>Application: the application is a renewal of a previous agreement (NIC-302004-P7B0P, approved 16 December 2014) for NHS East and North Hertfordshire CCG to continue to use data identifiable (weakly pseudonymised) at the level of NHS Number to provide intelligence to support commissioning for healthcare services.</p> <p>Discussion: DAAG queried the local data flows and the fact that the diagram within the application did not correlate with the text in the summary section. It was also noted that the local data flow information relating to Secondary Uses Services (SUS) was not present in the data flow diagram and it needed to be updated to reflect this, as it was not clear how local data flowed.</p> <p>DAAG noted that the fair processing notice on the CCG's website was inaccurate and misleading, undermining the legal basis for the data flows described in the application and needed to be updated in line with Information Commissioner's Office (ICO) guidance. The fair processing notice on the website needs to be accessible and accurate</p> <p>Outcome: Unable to recommend for approval.</p> <ul style="list-style-type: none">• Clarification was required with regard to the local data flows including updating the data flow diagram and summary as discussed.• The data flows described in the narrative and the data flow diagram should be mutually consistent, complete and accurate.• The fair processing notice did not contain accurate information and needed to be updated in line with ICO guidance, DAAG advised that the fair-processing information needed to be accessible and accurate.

NHS East and North Hertfordshire CCG – Risk Stratification (Presenter: Stuart Richardson) NIC-371018-K1P2X

Application: this application is to renew the flow of Secondary Uses Services (SUS), identifiable at the level of NHS Number for use in risk stratification. The previous application (NIC-302031-S0C2N) was approved by DAAG on the 12 November 2014.

Discussion: DAAG noted that the fair processing notice concerns raised in 2.1 above were exactly the same: fair processing notice on the CCG's website was inaccurate and misleading, and needed to be updated in line with the comments made in the previous application from this organisation, NIC-371050-X4H9L

DAAG raised concerns that data was flowing after the agreement had expired and members asked that the Chair of DAAG inform the SIRO, Rob Shaw, should the clarifications requested by DAAG not be provided by Friday 4th September

The data flow diagram contained within the application contradicted the text contained within the summary and this needed to be explained with regard to outputs and identification of data. DAAG also queried why the two applications from the same organisation contained completely different data flow diagrams.

Outcome: Unable to recommend for approval.

- Clarification was required with regard to the local data flows including updating the data flow diagram and summary as discussed.
- The local data flow data was not clear with regard to SUS and this information also needed to be included on the data flow diagram and summary.
- The fair processing notice did not contain accurate information and needed to be updated in line with ICO guidance, DAAG advised that the fair-processing information needed to be accessible and Stuart Richardson to provide back to DAAG confirmation of the above by Friday, 4th September 2015

Actions:

- The DSC team to speak to applicants with regard to fair processing notices
- DSC to provide the DAAG secretariat with a list of all expired DSFC agreements

CHKS Limited (Presenters: Garry Coleman / Netta Hollings) NIC-352414-W9M3F

Application: this is a request to amend an existing Data Sharing Agreement (NIC-292296-Y2M2K, approved by DAAG on 13 January 2015) to extend the current agreement past its expiry in August 2015 for six months only; to add in the purpose for the use of HES data; to incorporate the supply of data from mental health and learning disabilities data set and permit the linkage of that data with the HES data being supplied under the current agreement.

Discussion: DAAG raised concerns with regard to the addition of the mental health and local authority data and that the justifications provided were not persuasive. DAAG noted the work of CHKS Ltd in providing bespoke and analytical work to their customers, however more information was required around the type and use of data requested. DAAG clarified the details of linkage of data and bridging file information to ensure that individuals could not be re-identified.

DAAG agreed that the HES data only could be extended for 6 months, but could not recommend the mental health or local authority data release.

Outcome: Recommendation for approval subject to -

- The extension and renewal is for HES data only up to the end of February 2016
- The mental health / local authority information to be removed from the application.

University of Nottingham (Presenter: Dave Cronin) NIC-330562-P8S0R

Application: this application is to extend an existing Data Sharing Agreement (DSA) (NIC-170780-D2O5F) in order to authorise the ongoing retention and reuse of data for the bespoke extracts of HES Admitted Patient Care, Outpatient data and HES linked ONS data supplied for the purpose of academic research under the previous agreement.

Discussion: DAAG noted that this was a very large and potentially beneficial study. However, DAAG queried the size of the cohort requested and the amount of data required by the University as the full HES dataset seemed disproportionate to the purpose, (e.g. DAAG noted that the data released included men who would not be required for the study), so asked that data not relevant to the research project be removed from the application. DAAG noted that the ONS approval expires in April 2016, however DARS confirmed that there was an explicit obligation on all customers as part of their signed data sharing agreement to maintain their approvals otherwise the agreement would immediately expire.

DAAG were concerned that the project had commenced in 2013 but that there was no explicit or clear evidence of impact or dissemination to interested communities and groups including the 3rd sector, charities etc. DAAG asked that any future application should clearly state the impact to date and progress made.

Outcome: Recommendation for approval subject to -

- Data set to be appropriate for purposes of the project including confirmation that the applicant will delete data not relevant to the research project
- Clear evidence of dissemination to appropriate interested groups such as charities, 3rd sector

CRAB Clinical Informatics Limited (C-CI) (Presenter: Garry Coleman) NIC-351722-W7D4N

Application: this application is to amend an existing Data Sharing Agreement (DSA) (NIC-321582-C0P0G) from a bespoke extract to a standard monthly subscription service and also extend the retention period of the agreement.

Discussion: DAAG queried the significance of moving from bespoke extract to standard monthly subscription but that the application was clear and informed. Garry Coleman explained that the move to monthly subscription meant that the organisation received the data on the same day each month, whereas bespoke the data was not received on a fixed timeline.

DAAG noted that a large amount of data would be released monthly and asked how the applicant was using the data and who the applicant's customers were, including the number of NHS organisations. DAAG noted that the applicant didn't appear to be applying a sub-licence for onward sharing of data and this was a real concern.

DAAG queried the N3 connectivity and Gary Coleman explained that the applicant accessed the server remotely via the secure connection.

Outcome: Recommendation for approval subject to -

- Clarity was required with regard to who the customers are
- Clarity was required with regard to how the applicant is using the data and if a sub licence is required. Should a sub licence be required the relevant wording should be included in the data sharing agreement.

University of Birmingham (Presenter: Garry Coleman) NIC-352300-D9R2G

Application: this application is to renew an existing Data Sharing Agreement (DSA) relating to bespoke extracts of HES Admitted Patient Care, A&E and Critical Care data supplied for comparative analysis in order to receive additional data for the same purpose described in DSA:

NIC-226671-S4Q7D

Discussion: DAAG asked for further clarity with regard the additional data requested and that the application did not adequately address why the whole data set was required. DAAG noted that within the application it was not clear what was new text and asked that future applications clearly identify new text clearly.

DAAG asked for clarity around the three projects and the data required and it was explained that data sharing agreements for the applicant contain a number of projects ensuring the applicant received one lot of data for use across different projects within the agreement.

DAAG noted there was little information with regard to project one and that it may be beneficial for the applicant to use the same example throughout the application, building on examples and how it meets benefits and outputs.

Outcome: Recommendation to approve subject to

- Clarification was required as to why the whole data set is required
- More information was required with regard to project one and the application updated accordingly

IMS Health Technology Services (Presenter: Garry Coleman) NIC-324360-T8R3T

Application: this application is to amend and renew an existing Data Sharing Agreement (DSA) relating to Standard Monthly extracts of HES Admitted Patient Care, A&E and Outpatient data supplied for comparative analysis.

Discussion: DAAG raised concerns with regard to the roles of the two organisations listed and required clarity around the data controller arrangements. DAAG noted that the application was confusing and needed greater clarity throughout the application around the roles of the two organisations and which organisation did what. DAAG also noted that there was a distinct legal difference between the terms 'joint data controllers' and 'data controllers in common' and that the application should be consistent about the data controller model. DAAG noted that a previous application had contained SunGuard as the data processors and asked why they had now been removed.

DAAG queried who the customers were of the applicant band noted the ambition to extend their customer database. However, DAAG felt that this was a very small customer base and greater clarification was required around who the actual customers were, due to the large amount of data requested. DAAG did note that it had previously approved some applications from organisations with few or no actual customers at the time.

Concern was raised about the data used to identify clinical trials sites and they should always be ethically based with results published across relevant medias. DAAG requested further information with regard to the clinical trial tool and on-line heat map in Service 5 (Clinical Trial Site Identification) and what the added value would be and who the potential clients would be. DAAG noted that the National Institute for Health Research had submitted an application on the 14 October 2014 for a publically funded on-line heat map for clinical trials and DAAG suggested that the applicant may wish to benchmark against this heat map to justify the need for a new commercial map.

DAAG also asked if the health benefits were direct enough and ensuring they complied with the Health and Social Care Act 2012, however it was noted that previous applications had been approved that contained indirect health benefits.

DAAG raised concerns with regard the data protection registration and IG toolkit information contained within the application and that it was incorrect and needed to be updated with the correct IMS organisation details.

	<p>Outcome: Recommendation for approval for services 1 to 4 for 6 months only, subject to -</p> <ul style="list-style-type: none"> • Clarification with regard the role of the organisation as data controllers and to ensure clarity throughout the application as which organisation has what role • Clarity as to the removal of SunGuard as the data processors • More information was required for service 5 including added value and client base • DPA registration be updated • The IG Toolkit be clarified and updated • Sub licencing arrangements should be added to the DSA. • DAAG noted that should an application come back for consideration this should contain further information around health and social care benefits, including examples, and evidence of a growing customer base. <p>Civil Eyes Research Limited (Presenter: Garry Coleman) NIC-369539-S1P8K</p> <p>Application: this is a renewal request for HES Admitted Patient Care, Critical Care, Outpatient and A&E pseudonymised and non-sensitive data to retain data years 2012/13 to 2013/14 and additional data year 2014/15. The data will be used to provide analysis on the use of Pathological services and use the HES data to provide analysis of clinical performance and benchmarking information to NHS organisations.</p> <p>Discussion: DAAG noted that the purpose was too generic and that the main outputs were workshops asking how the applicant was working collaboratively with the NHS. Further information with regard to the applicant's work with Keele University was required and the projects undertaken.</p> <p>DAAG asked for further clarity around how many workshops and projects had been undertaken and who the applicant had been working with. DAAG noted that a future application would need to clearly show the impact of the workshops and projects for the services they were providing, clearly explaining the health and social care benefits with examples.</p> <p>Outcome: Recommendation for approval for an extension of 3 months only, with no new data being released to the applicant noting a future application would need -</p> <ul style="list-style-type: none"> • Further information around the projects involving the Universities and clarity as to which Universities are involved. • Clarification with regard to how much data the applicant requires and further information around intended purpose and use of that data.
3	<p>Rob Shaw (RS) – SIRO update</p> <p>RS attended DAAG for this item only to advise and consult members on the interim arrangements during the transition from DAAG to IGARD and subsequent appointment of a permanent chair. Members discussed the implications of recent changes in the HSCIC executive board and their potential impact on DAAG.</p> <p>RS thanked members for their critical role in supporting the HSCIC and protecting patients.</p>
4	<p>AOB</p> <p>The Acting Chair thanked Dr James Wilson for his useful insights at this first attendance at DAAG</p>

Summary of Open Actions

Date raised	Action	Owner	Updates	Status
04/08/15	DAAG Secretariat to send DAAG members a copy of the HSCIC Board minutes that covered the discussion of changes to HSCIC Executive Director team and Caldicott Guardian arrangements.	DAAG Secretariat	13/08/15: The relevant Board minutes had not yet been published. 18/08/15: The next meeting of the Board is on the 23 September after which the draft minutes will be agreed. DAAG secretariat to circulate following publication 25/08/15: ongoing – DAAG secretariat to circulate once ratified at the 23 September 2015 meeting	Open
04/08/15	Steve Hudson to provide a diagram of current DARS team setup.	Steve Hudson	13/08/15: It was agreed that Terry Hill would pick up this action. 18/08/15: The action has been chased with Terry Hill via the Secretariat 25/08/15: DARS structure circulated to members for information	Closed
13/08/15	Garry Coleman to confirm within eight weeks whether the privacy notices for Leeds City Council, Lincolnshire County Council and Norfolk County Council have been appropriately updated.	Garry Coleman	18/08/15: Garry Coleman to update DAAG at the next board meeting 25/08/15: Garry Coleman updated members that these would be updated 8 weeks from the DSA being signed	Closed
13/08/15	Stuart Richardson to ensure that the privacy notice for Castle Point and Rochford CCG is appropriately updated.		18/08/15: Stuart Richardson to continue to work with applicants and feedback update at future DAAG. 25/8/15: Stuart Richardson to update members on the 8 September with regard to fair processing notices in general and progress to date – Secretariat to add to agenda as discussion item	Open