Digital North West London:
Information Governing Group Minutes

Thursday 7 December 2017

British Dental Association (09:30-12.30)

Minutes

NOTE: By agreeing to these minutes, you are providing formal approval of the decisions therein in your capacity as a signatory of the Digital ISA and a Data Controller (please refer to Decision Log).

ATTENDEES

Name	Role	Organisation	IN.
Abhilash Abraham	Security and Cyber Lead	NWL Collaboration of CCGs	**AA**
Amanda Lucas	WSIC Programme Lead	NWL Collaboration of CCGs	**AL**
Bill Sturman	Director, Informatics	NWL Collaboration of CCGs	**BS**
Calum Leafe	Data Protection Officer	Imperial College Healthcare Trust	**CL**
Christine Dunne	Deputy Director, Primary Care Systems	NWL Collaboration of CCGs	**CD**
David Grange*	IG Manager	Patient Knows Best	**DG**
David Stone	Managing Director	Kaleidoscope Consultants	**DS**
Dr Laurie Slater	Clinical IG Lead	CWHEE/NWL	**LS**
Ernest Norman-Williams	Information Governance Manager	BHH CCGs	**EN-W**
Ian Riley	Director of Business Intelligence	NWL CCGs	**IR**
Jan Boucher	Information Governance Manager	Tri Borough	**JB**
John Norton	Lay member		**JN**
Philip Robinson		NWL Collaboration of CCGs	**PR**
Raj Seedher	Information Governance Manager	Brent Council	**RSe**
Ritu Sharma	Information Governance Manager	The Hillingdon Hospital	**RSh**
Sanjay Gautama (Chair)	Caldicott Guardian and Chief Clinical Information Officer	Imperial College Healthcare NHS Trust	**SG**
Xavier Yibowei	Programme Manager	NWL Collaboration of CCGs	**XY**
In attendance			
Rihanna Kamara (item 6)	Implementation Lead	Decision support for radiology imaging requests	**RK**
Katie Stone	Minutes	NWL IG Support	**KS**
Apologies if this list is incorrect. Please email nwl.infogovernance@nhs.net with any corrections. (*On the phone)			

1. **Welcome and introductions**

   SG welcomed everyone to the meeting, including those on the phone. All those attending were asked to sign in on the attendance sheets.

2. **Conflicts of interest / declaration of interests**

   David Stone is managing director of the IG consultancy Kaleidoscope Consultants. Katie Stone works through Kaleidoscope Consultants in her role as IG Support Officer.

3. **Minutes of the meeting held on 2 November 2017**

   The minutes of the meeting held on 2 November 2017 were confirmed as an accurate record of the meeting and will now be published on the WSIC web site.

4. **Actions log**

   Updates were given and are shown on the table below. Items that were shown as closed have now been removed. New items from this meeting have been added.

5. **De-identified data access contract and London North West withdrawal**
   i.   Implication for WSIC data if London North West withdrawal from ISA (AL)

   Outcomes of consultation on deidentified data access contract (KS)
   KS reported that she had issued the contract for consultation to all signatories (around 550 recipients). The paper set out all the responses. Mostly people wanted clarification over why they were being contacted and, other than London North West, no substantive objections had been raised.

   - LS said highlighted the importance of greater support in primary care in understanding their responsibilities as data controllers. LS would write to primary care colleagues and direct them to the minutes (particularly the decision table) published on the web site, but there needed to be more thought about separate communication if important decisions were being made
   - The group also agreed that the mechanisms around consultation and decision making should be picked up by the new ISA work about to be undertaken.
   - It was pointed out that all meeting minutes are published and the data controllers would be able to see decisions and issues if they were concerned.

   Decision:
   The contract could be used if DACBeachcrofts were content.

   Action:
   AL [IR] agreed to contact DACBeachcrofts for them to validate that all their

concerns had been addressed and the version circulated was the final version as agreed by them.

Outcome of conversations with London North West Healthcare NHS Trust (SG)

SG reported to the group on a phone conversation with Sonia Patel (SP) (with Laurie Slater and David Stone also on the call earlier 7 December 2017.

As things stood, London North West Healthcare NHS Trust had given notice that they would withdraw from the ISA as SP had not received any satisfactory level of assurance about her concerns which left her with a risk profile she could not enter into on behalf of the Trust.

SG restated the concerns as:
- What are the data controller liabilities for anonymised information and its use, access and the process of anonymisation.
- There had been a low risk assessment given to WSIC, but there was no detail about what low risk meant in reality or even detail of what the measure meant (eg against some established standards).
- There needed to be greater transparency about data projects benefitting from using deidentified data, but the web site was out of date.
- The risk register need to reflect the gaps in terms of understanding the assurances ISA re-write and anonymised data.
- Great visibility of historical risk caused by past sharing of data.
- Confirmation that all Beachcroft concerns had been addressed in the current drafting of the contract for use with non-signatories.
- Progress report on the GDPR-compliant ISA and a commitment to a specific timetable.

Action:
AL [IR] agreed to seek advice from DACBeachcrofts over any risks from past data sharing.

AL [IR] agreed to seek greater clarification over the 'low risk' assessment.

AL [IR] agreed to update the project tracker and post it on the web site.

DS to confirm to Sonia the timetable for the work on the ISA and give a detailed update on progress at the

next Governing Group
meeting.

KS to ensure all minutes
are published after
approved at the following
meeting.

Implication for WSIC data if London North West withdrawal from ISA (AL)

SG confirmed that the current request to withdraw from the ISA stands for London North West Healthcare NHS Trust and there was three months to complete the request. If her concerns are resolved then SP might withdraw the notice. However, while her concerns are resolved, SP does not want colleagues in London North West to have access to the data and she requested a list of those recently trained by the WSIC team. SP also needed to know who were current active users and seek a specific instruction to withdraw their access if that was her intention.

Action:
IR agreed to write to SP to confirm her preferred treatment of active and newly trained users.

RSe queried whether it was right that others could request access without going through a central authority (the Caldicott Guardian, CG)? Others felt it was not practical for the CG to be responsible for approval all data requests for access to what is already an approved system. But it was agreed that this situation had raised questions to resolve in the new ISA about how people withdraw their data, or how the group might handle a situation where they wanted to expel an organisation. XY stated that any exit arrangement should have a significant lead time because it might involve system reconfigurations.

SG queried with DG from PKB whether they had ever had to stop data flowing and DG promised to feedback on how this might have been handled.

LS felt that this situation (especially the delay in picking up the seriousness and implications of the concerns expressed for London North west) exposed the lack of IG capacity available to the Governing Group. This issue had occurred when there was a vacuum in terms of support and it seems likely that the group only gets busier. It was agreed that SG and LS would talk to BS about how the project should develop, particularly in terms of ongoing support for IG and administration / secretariat support.

Action:
SG and LS to meet with BS about resourcing for IG.

6. Requests for IG support

Report on new system and requests agreed by Chair's action

KS explained the new tracker and the system for making requests. Members in the Governing Group were able to see and challenge requests approved by Chair's action between meetings, and review overtime the profile of support given to projects.

SG welcomed the work on the tracker and explained that he and LS would like to avoid Chair's action as much as possible and have a more forward looking approach to IG work.

Clinical decision support for radiology imaging requests (Rihanna Kamara, Implementation Lead)

Members of the GG had papers relating to the project. KS explained that the need had been assessed at £6,000 + VAT for five day's senior consultant support. The work would involve a DPIA, reviewing the FPN, mapping data flows, checking for any outside EA issues (forensic look at architecture), and contract reviews.

RK explained that the project team did not have specialist IG expertise and they needed advice and guidance to ensure that their work appropriate considered all data privacy needs. There was no specific money put aside for this support and they had not yet looked internally for resources (which cut across more than one organisation).

The request was whether the GG were happy to spend the limited money that BS has provided to support this request. The GG felt that GDPR-based projects must be top priority, along with other projects with a broad reach (whole systems, CIE, etc.). It was queried if the project had been discussed at the Portfolio Board and where it sat within the priorities for NWL. Others felt that the Trust's IG teams should be doing this sort of work. Everyone agreed that IG must be a fundamental building block in the design of all projects.

SG stated that in his view projects should be budgeting for IG support as they do any other essential part of their project. It was essential that an IG expert sign-off the project before any data started flowing. BS felt it was a reasonable approach to ask partners to contribute to price of assurance. For each project an amount should be put aside for IG.

Decision:
RK was informed that the GG would not fund this request for IG support, but suggested that she seek Trust internal support for this important work.

BS will inform Tony Willis that he will need to find the funding for the IG support from him project budget. And that the project must be reviewed

at the Technical Design Authority before returning to the GG.

KS was asked to add to the IG request form the following fields: Has it been to Portfolio board? / Technical Design Authority? Are there any new systems?

7. Consultancy arrangements (including ISA)

DS confirmed that there are two proposals agreed by BS. NWL ISA valued at £24,000 and the WSIC DPIA valued at £12,400. A project manager would be appointed in December 2017 and arrangements to kick off these two projects would get underway.

The work will need more detailed scoping as the current quotes do not include work on communications, getting data controllers to adopt the ISA, or any work supporting GPs with GDPR compliance (discussed further below).

BS expressed the need for the group to increase their compliance with good procurement practice going forwards. This needed to include a decision on which organisation's procedures would be used. At this time BS supported a single supplier approach for the use of Kaleidoscope Consultants for this crucial work leading up to May 2018 as their depth of knowledge of the IG work at NWL Collaborative made them uniquely placed.

Action:
KS to gather a list of consultancies to start work on a preferred supplier list for NWL IG work.

Issues that were raised in the meeting:
- Brent fully understanding the new role of the data processor and their risk exposure
- Needs to be aligned with DPA 2018 and that is not yet finalised.
- High levels of engagement needed (link with a piece of work by IG Support on distribution lists and up to date contacts across all signatories).
- Should try and recycle/refresh existing materials wherever possible and not ignore good work that has been carried out in the past.
- Plan engagement with a large range of stakeholders (lay members, LLMC, primary, secondary, etc.)
- Find streamlined way to gain new signatories, or explore whether people do need to re-sign – review lessons from previous project.
- Becoming a signatory needs to come with clear guidance on what it means to be a data controller – obligations to the group.

- Need a pan-London communications meeting to discuss a joined-up approach.
- There should be greater emphasis over time on building the knowledge and skills of the in-house IG functions.
- DS should attend GG at Chair's discretion / as needed.
- Ensure that the existing agreement is in place until the replacement goes live so there is no uncertain time between the two.

LS asked that a new quote was organised to cover the work on creating an educational pack for GPs on GDPR. This was linked as it would help with engagement when approaching them on the more detailed ISA work. Suggested we engage with the GP Federation to ask them to help with our education component. LS and SG were going to talk with BS first and then commission the quote from Kaleidoscope.

Action:
LS and SG to discuss scope of GP support work with BS and then commission quote from Kaleidoscope.

8. **Review of Public Facing Materials (including discussion on possibility of re-forming the Communications Sub-Group and review of existing terms of reference).**

A summary of the main paper by Kaleidoscope Consultants was tabled at the meeting. AL explained to the GG that the WSIC programme were keen to review whether current public facing notices were clear and fully covered any new purposes that had developed over time.

The report showed that there was room to improve the exposure for some age groups and for some languages. There was mixed evidence on how accessible the materials were at different sites (which had been visited).

DS commented that there was potential to extract data about languages from the check-in kiosks at some locations (where patient's select their language by choosing a flag). He noted that materials designed for children were often better used.

SG commented that relying on publication on a web site as minimum compliance was not satisfactory when as many as 28% of the population were functionally illiterate and don't have access to electronic communication. He stated that the messages on direct care must be communicated in a clear and consistent way and these materials were essential to those efforts.

JM congratulated the team on producing this report and hoped that the good work would continue.

A recommendation of the report was to re-form the communications sub-group and this was supported by the GG. It was suggested that it should include communication expertise from signatory organisations where available. The larger data controllers would be invited to nominate people to join the sub-group once formed. JM agreed that he would join as a

member (and maybe Co-Chair).

RSe suggested that a glossary of terms might be usefully added to some materials. PR raised a concern over the efficacy of offering materials in other languages and it was agreed that it would be offered, but the versions would not be produced unless requested.

Action:
KS to review the terms of reference of the previous group and bring a draft to the next GG.

WSIC programme to take forward the other recommendations (update key publications and notices, separate the web site to promote WSIC, and encourage partners to public a link from their web sites)

9. **Report of activities from the Dataflows, Security and Access Sub Group meetings**

RSe reported that the sub group meeting held on 23 November approved seven data access requests for de-identified data sets. It had demonstrated that there was lots of excellent work going on and greater awareness of the WSIC programme and what it might offer. The sub group were keen to develop their communications so that the breadth of current projects encouraged others. It would also help track progress over time and help demonstrate direct patient care value.

The sub-group had reviewed the template letter for WSIC to respond to subject access requests and some amendments were agreed. The approach was approved and would go ahead.

The group had reviewed the results of the PEN test and AA agreed to send more detailed feedback to the WSIC programme after the meeting. AA confirmed that this was done.

The sub group had agreed a new approach to access controls including a further self certification based on the practice code.

10. **WSIC programme update (including CIE/WSIC integration)**

AL brought to the attention of the GG the pack of information in their papers. It showed that there were 300 returning users and that all use was increasing. There was an increase of users involved in direct care.

It was noted that AL, current programme director for WSIC Dashboards, was departing in December 2017 and this was her last meeting. The GG were assured that Ian Riley and Kavitha Saravanakumar would be taking on the relevant responsibilities for the programme.

SG thanked AL for her work and wished her well with her next venture.

11. Discover programme update

AL brought to the attention of the GG the pack of information in their papers. Phase 1 of the programme has been agreed with Brent CC as lead data processor for WSIC. Brent CCG had endorsed the recommendation to adopt MTC Media and the University of Dundee as sub-data processors, and to allow the Discover Register to link to WSIC. AL did explain that Brent had been cautious in their approval and there was a need to continue to engage fully with them about the programme. Phase 2 was embarking early in 2018.

12. TPP Enhanced Data Sharing Model (EDSM)

LS explained that there will be three groups, each with a different approach to sharing data:

   i.   TPP will share
   ii.   Require validation (and there will need to be a process.
   iii. TPP won't share (expected to be small)

The decision needed was how these groups would be selected. i) All ISA signatories would be in the 'will share' group by default. ii) Others would need considering on a case by case basis and it was agreed that LS would draw up a list and bring it back to the GG to approve. iii) The GG felt that they must not have a banned list, but should define some principles and a process for making decisions. There were not expecting to see anyone on the 'won't share' list to begin with.

Action:
LS to create the validation list for consideration.

LS to suggest some principles and a process for making a decision to stop TPP sharing.

13. Data Controller Console

DCC team were invited to attend the GG or have a special meeting with NWL, but instead offered to run a webinar to demonstrate the DLL and take questions. They are also seeking a super-user from NWL to attend their meetings.

SG re-stated that the DLL was not designed as a GDPR compliance tool and that the group

were more likely to have it develop in a way that was useful to the GG's objectives if they engaged fully with the team. The DCC team were seeking to launch and then develop based on need. SG felt that NWL might engage in what was essentially a funded pilot. LS also recommended engaging more fully with DCC and then try and influence the direction of travel for the project.

RSe commented that this was not helpful as they had to find ways of delivering their GDPR compliance and may end up having to duplicate effort. RSe and PR felt that there may be alternatives that tracked the ISA (which was the current function of the DCC and also supported GDPR compliance.

DS reminded the group of his conflict in this area as his company has a GDPR compliant mapping tool.

IR sought to clarify if NWL had taken a strategic decision that its member organisation should use DCC. RSe wondered if the GG was the right forum for discussion as it was not an IG tool – the sharing agreements would not be public facing and so no transparency for patients.

XY suggested that the DCC could help with re-signing controllers to the new ISA if that was the route the project took.

Action:
[No specific action was recorded]

14. **Quoracy at meetings and representation of health and social care (now and in any future governance arrangements)**

RSe explained that the sub-group had raised the issue of quoracy at meetings and whether it needed to be a mix of healthcare and local authority representation. The meeting on 7 November 2017 had approved clinical data access requests, but only LA controllers had been on the call. In general only LS was present at Dataflows, Security and Access sub group meetings, yet some of the requests were hard to assess without greater clinical input.

It was agreed that there should be efforts made to increase attendance at the sub group from a broader range of participants.

Action:
RSe to discuss with the sub group how best to increase clinical engagement with their work.

15. Date of the next meeting

The next meeting was scheduled for Thursday 4 January. It was decided that this meeting should be cancelled and the items outstanding from this meeting heard in a combined meeting (with the Dataflows, Security and Access sub group sub group) on 18 January.

ACTION (Immediate):
KS to inform PMO to cancel January and set up 18 January meeting as agreed.

The meeting closed and it was agreed to carry forward outstanding items to meeting on 18 January 2018:

- IG Toolkit and Cyber Security
- Recommendation Report from National Audit Office on the Investigation and Lessons learnt as a result of the recent Cyber Attack North West London (NWL)
- Cyber Security Maturity Model and Cyber Security Toolkit
- Review of Risk Register