North West London Collaboration of Clinical Commissioning Groups

Digital North West London

JOINT MEETING MINUTES
Part 1: Information Governing Group
Part 2: Dataflows, Security and Access Sub-Group

Thursday 18 January 2018 (09.30–13.00)
British Dental Association, 64 Wimpole Street, London W1G 8YS

NOTE: *Items were taken out of order in the meeting, but are reported as per the agenda in these minutes.*

1. Welcomes and introductions

Attendees
David Grange, IG Manager, Patients Know Best (on the phone)
Ernest Norman-Williams, IG Manager, BHH CCGs,
Laurie Slater, IG Lead, CWHHE
Phillip Robinson, Imperial College Healthcare Trust, IG Manager
Ritu Sharma, IG Manager, The Hillingdon Hospital
Sanjay Gautama (Chair), Caldicott Guardian and CCIO, Imperial College Hospitals NHS Trust

In attendance
Amanda Lucas, Project Manager, Imperial College Health Partnership (Discover project)
Andrew Harrison, Developer, Imperial
Anish Modgil, Project Manager, Health London Partnership (Data Controller Console)
Brian O'Toole, Tech Project Manager, NWL Collaboration
David Newton, IG Adviser, Kaleidoscope Consultants (Discover project)
David Stone, IG Adviser/Consultant, Kaleidoscope Consultants
Ellen Baldry, Project Manager, Kaleidoscope Consultants (ISA/DPIA)
Ian Riley, Director of BI, NWL Collaboration
Katie Stone (Notes), Kaleidoscope Consultants (IG Support Officer)
Kavitha Saravanakumar, Deputy Director of BI, NWL Collaboration
Lynn Young, Senior Consultant, Kaleidoscope Consultants (ISA/DPIA)
Sophie Gomez, IG Research Officer, Imperial
Suhaib Rashid, Development Lead, WSIC Programme

2. Apologies for absence

Apologies were received from:

- Abhilash Abraham
- Jane Wilmot
- Janice Boucher
- Raj Seedher

3. Confirm that the meeting is quorate

The meeting was not quorate. It was agreed that the next meeting scheduled for 1 February 2018 would be extended to ensure decisions could be validated.

ACTION:
KS to ask PMO to extend the times of the Governing Group meeting on 1 February 2018 to 9am to 1pm. All outstanding agenda items should be moved to the new agenda (and will not be shown as individual action points).

4. Conflicts of interest

David Stone who advises the Governing Group on information governance is an external consultant from Kaleidoscope Consultants. Katie Stone who is the interim IG Support Officer for NWL Collaboration is supplied by Kaleidoscope Consultants.

PART ONE: INFORMATION GOVERNING GROUP

5. Minutes of the Governing Group meeting held on 07 December 2017

The meeting was not quorate and so the minutes could not be approved. They will be reviewed at the Governing Group meeting on 1 February 2018.

6. Review of Action Log

The actions were not discussed and so will be reviewed at the Governing Group meeting on 1 February 2018.

7. Data Controller Console (Anish Modgil)

Anish Modgil (AM) explained that he was the new project manager and had only recently joined the project. Amy Ford, the IG Adviser on this project, sent apologies as her travel was disrupted by the weather problems that morning. There had been a meeting the day before to review the strategic direction of the Data Controller Console (DCC) project. Mike Part had been part of the meeting.

AM explained that going forwards it had been agreed that the focus of the DCC must be on

supporting organisations with their GDPR compliance. This was the expertise Amy Ford would be brining to the project.

In terms of roll out, there had been a decision to hold on promoting in the third sector. Xavier Yibowei was the super-user for GPs. There was a need to increase deployment in secondary care sector. AM stated that it would be helpful if NWL would supply super-user resource to help with deployment to this sector. The GG commented that this was not funded and AM said he would look into this as part of project budget.

Other plans were to develop a public facing web site so that individual data subjects could see what data is being shared. Future develops might link this to a national opt-out process, but this was not a current priority. Members of the GG had concerns over the focus on consent, and AM assured them it was just something that might in the future be added to functionality and it would not form part of current plans. The GG asked the project to consider how the population of people who work and seek treatment in London, but live elsewhere will be handled by the project.

Agreed next steps for the project were for AM to prepare a detailed project plan which showed what the DCC would achieve by the May 2018 GDPR deadline. AF and colleagues were doing a full gap analysis for the DCC against GDPR and that would then drive the development agenda.

SG commented on the ambition to support compliance and stated that it would not guarantee overall compliance with GDPR. AM explained that it was a tool to support compliance within its intended arena.

DS asked if the functionality of the DCC had been mapped to the Data Controller requirements under GDPR so that the project could promote the benefits to DCs of adopting the product. It was suggested that this might be done for each sector.

It was agreed that a set of short 'marketing' documents explaining the DCC, its purpose, how it fits with other pan-London initiatives, and its benefits (linked to each sector) would help recruit organisations to the project. It should include development plans (in brief), timescales, how it is costed, and something on future expectation on the cost. Prospective users might benefit from seeing the DCC populated with some ISAs. The materials should also set out what the expectations are from the project team (support, etc.) and from the organisation itself in terms of set up. LS would be happy to support recruitment of primary care if this sort of support document existed.

REQUEST:
DCC team to consider producing a set of short 'marketing' documents explaining the DCC, its purpose, how it fits with other pan-London initiatives, and its benefits (linked to each sector). Include

development plans (in brief), timescales, how it is costed (now and in future), plans for demonstrating the DCC at work, expectations are from the project team (support, etc.) and from the organisation itself in terms of set up.

PR expressed his concern about the DCC. He stated that the market place already has products that have similar functionality. He queried why partnership opportunities were not being explored. SG stated that he felt it was too late for that approach and that it was important that NWL colleagues engage with the DCC to influence the development in a direction that was most useful for the organisations we represent. LS agreed that the DCC may not be prefect, but felt that NWL had agreed to use it and should now move forwards. PR stated that in that context, the different organisations could not be expected to resource the project informally through attending meetings to help with development work.

RS said that Hillingdon were already using the DCC and felt it was a useful addition. They did need additional support to upload the ISAs. AM explained that there would be increased people working to support users and a generic mailbox introduced to help people requesting support. There was also a weekly web-ex for users.

It was agreed that AM should be invited back to discuss progress with the DCC and return to the issues discussed. AM was happy to receive emails direct at anish.modgil@nhs.net.

ACTION:
KS to issue invitation to future meeting (when the promotional materials are ready), including to discuss a super-user and general funding issues.

ACTION:
GG members to email AM direct with any further queries related to their organisations.

8. Imperial College Health Partners: Discover Expansion (Amanda Lucas and David Newton)

AL explained that this was a project to introduce a 'consent to contact' flag to the WSIC data set. The work was closely following the SHARE work at University of Dundee and was benefitting from their contracts, ethics approach, etc. When discussed at the GG previously a request had been made for more detailed work on procedures and that was what the team were presenting today and in the paper which was circulated in advance.

Researchers would not have access to any patient data, only deidentified aggregate data. If a data subject who had the flag is selected for a research study then the Discover team would get in touch with the patient to see if they wanted to participate. There would be a limit on the number of times each year anyone was contacted and there would be a process for withdrawing consent. Opting in would be entirely voluntary through a website form which would match people to the WSIC data by their NHS number.

The project was in an advanced state and ready to launch in early February. The web site was built and Brent CCG has signed the DPA for the new data processors (University of Dundee and MTC Media). Today, the team were looking for:

- Approval of the model as set out in the paper
- Proceed with getting two Group set up: an Access Committee and a Governing Group.
- Feasibility dashboard pilot (with lessons learnt considered before a full launch)
- Clearance to accept applications.

SG asked why, if the data was WSIC data, couldn't the access requests be considered by the Dataflows, Security and Access Sub Group. AL felt there was a different audience for these requests as they would be clinical and also require contribution from those involved in research work. This would be in line with the access committee set up to review access requests for the SHARE programme.

DS felt that DSA Sub Group might be suitable for access requests if they could adopt more agile working practices and narrow their scope to just access requests. Membership would have to include research experts. It might be possible to post forms in a collaboration noticeboard online to encourage feedback and review virtually them so that the requests went to the full committee with a clear recommendation. The more focused approach would also require that the Operations and Security Group previously discussed was now formed so these issues were not discussed at the DSA sub group.

LS asked how risks of breaches to the dataset were being mitigated. IR confirmed that this was the issue that was being discussed with Beechcroft in the context of the questions raised by London North West. SG wanted to understand any additional risks to data controllers as a result of Discover and requested that ICHP consider whether any indemnity could be provided to data controllers to mitigate any residual risk.

DECISION NEEDED:

The meeting agreed the programme move forwards (using the DSA Sub-Group for Access Requests with an extended audience). The recommendation needs to be ratified by a quorate meeting.

ACTION:

SG requested that all GG attendees read the papers provided ahead of a short validation discussion at 1 February Information GG meeting.

ACTION:

KS to ensure that it is logged with the team that research issues are more fully addressed in the new ISA.

ACTION:

ICHP to explore the additional risks to data controllers as a result of Discover and consider whether ICHP could indemnify data controllers to mitigate any residual risk

ACTION:

ICHP to work on the terms of reference for the Access Sub-group to include membership and responsibilities as defined in the proposed Data Research Access Group (DRAG)

9. Requests for IG support

The up to date tracker was noted. Three requests were waiting for a decision.

IG support request for Ambulatory Emergency Care Urgent Referral Tool (Andrew Harrison)

AH explained that they were aiming to deliver the tool to local GPs who wanted access to help with winter pressures. It had been agreed that the first iteration of the work had not be suitable in IG terms, but it had now been reviewed to ensure the specification was appropriate.

It was pointed out that John Kelly was working on another solution for referrals of this nature which would be ready to implement in August 2018. This meant that the tool would be obsolete in about six months. SG felt that no one from the project had appropriate engaged with ICHT and that it might be incorrectly perceived as an ICHT offering to the sector.

ACTION:

It was agreed that there needed to be a meeting with ICHT and other stakeholders before the project could progress. This meeting should include project and ICHT. LS and Christine Gunn should be copied in so they were aware of progress.

SG left the meeting. KS was asked to chair the remainder of the meeting.

Care Homes technology

Brian O'Toole was requesting IG support for a new clinical advisory services available via 111. It would support care home workers at all times and help with crisis management when a situation is deteriorating. Essentially provides virtual access to a GP for people who are in a care home. There had been a soft launch in December, but the services was being increased and they hope to go fully live in March 2018. They are preparing impact assessments for privacy (PIA) and security (SIA). The service offers video and Skype technology for consultations. No recording will take place and medical professionals would be expected to take contemporaneous notes in common with a more traditional face to face consultation (and post-event messaging will be possible back to EMIS/System One.

Kaleidoscope Consultants had given a quote for the PIA based on information available which was under £5,000. This was on the basis that a security assessment of Skype and Docabo was out of their scope (and would be handled by the security team).

The project team have the funds from John Keating, but not the resources and need permission of the GG to get agreement to access Kaleidoscope (ie commission the job).

ACTION:

The GG agreed that it was a reasonable request. Given the urgency, it was agreed that it would be considered as Chair's action after the meeting and then reported to the next GG.

Data cleanse for NWL Data Sharing Agreement Signatories (Katie Stone)

This proposal had arisen after problems gaining data to carry out the consultation into the de-identified data terms and condition. There had been a number of bounce backs and also some addressees who did not understand why they were being contacted.

KS was asking for support for to carry out a thorough review of signatory contact data to ensure that an up to date register was kept, with information for how Data Controllers wished to be informed about meetings, decisions, projects, etc. The immediate benefit of the work would be an up to date to be used to enhance engagement and communication and to help with re-signing work on the ISA.

It was thought this work would be a maximum of 48 hours (£3,600) and would need some way of collecting the data and then storing it so it could be accessed and updated with ease. This data would be shared with the WSIC programme who also struggled to have up to date information about the right contacts within organisations.

LS questioned whether it was really necessary and whether the data existed. He suggested contacting Christine Dunn to explore what was already available.

ACTION:

KS to undertake an initial review of what data sets are available and general evaluation of their accuracy and usefulness taking no more than one day at the rate quoted (£600). Subject to the outcome, Bill Sturman would need to be approached to approve any further work/funding.

10. Update GDPR compliance projects – ISA, WSIC DPIA, GP support

DS explained that the GP support proposal was still outstanding because he had begun exploring partnership opportunities with a commercial company who were creating a platform to support GPs with GDPR compliance. The GG were interested in DS exploring this if it came with acceptable and limited strings attached (some light branding, but not much more). DS said this was understood and he would report back on his discussions.

DS introduced Elle Baldry (project manager) and Lynn Young (subject matter expert and principal author) to the GG. They were the main project team for delivering the revised ISA and the DPIA. DS stated that the GG could expect to discuss this project at all their meetings from February to May and that the meetings themselves were considered major project milestones with set deliverables to each. A project plan setting this out would be shared with the GG. By 1 February, the GG would review the first draft of the overarching ISA.

DS explained that it would not fall to the GG group to run the engagement events for every sub schedule. Signatories to the schedule will be responsible for doing that themselves. The GG will need to run engagement for the overarching ISA and the main schedules affecting all signatories.

It is intended to use the DCC to publish the ISA.

DS emphasised the need for the Communications Sub-Group to be re-formed so it could direct the work on engagement. It was suggested that Amy Darlington (Director of Communications and Engagement at Imperial College Health Partners) would be a good candidate for Chair. John Norton had already agreed to be Deputy Chair at an earlier discussion. Once appointed, the Chairs would need to invite members, review and agree terms of reference and set up a schedule of meetings. Support arrangements for the group will need to be agreed.

ACTION:
DS to share project plan for ISA with GG.

ACTION:
KS to draft invitation for SG to issue to Amy Darlington inviting her to Chair a communications sub group and set up initial discussion about the work with DS and the project team.

11. WSIC Programme Update

IR brought the groups attention to the slides that had been circulated updating the GG on the progress of the programme.

12. Review of WSIC communication material

The GG welcomed these updated notices and hoped they would now be displayed prominently in organisation. They understood that they were a pragmatic interim solution ahead of a newly drafted modular, easy to read privacy notice based on pictograms which would form part of the ISA work.

13. Summary of PEN test actions

IR reported that the PEN tests had found some minor issues found and AA had also sent through his comments on the original report. The WSIC team were working with CSU to address these. All issues were expected to be closed by 19 January 2018.

14. Additional data feeds

Community data (WSIC programme)

This request is to bring data into WSIC and in this context the GG were happy to recommend that the organisations could contribute to the data set. But they were not to be access the WSIC data themselves as they were not signatories to the ISA.

The receipt of data was subject to a due diligence exercise on the organisations to ensure they were sharing lawfully and that there was adequate communication in place telling their patients what they were doing and why.

DECISION NEEDED:

The GG are asked to confirm that the community groups could send data to WSIC with appropriate due diligence taking place on their legal basis for processing and communication with patients.

Referrals data (WSIC programme)

This data would come from organisations that were already signatories, but would expand into referrals. LS questioned the quality of the data from the sources listed and asked whether a data subject might be surprised their GP knew about a referral. He wanted an evaluation of worst case scenario. LS also asked whether this approach would support the primary purpose of direct care.

It was agreed that this request should wait until the new ISA was agreed and make it more explicit that management of care was a legitimate basis.

DECISION NEEDED:

The GG are asked to confirm that they agreed that the request for referrals data should be rejected until such time as the new ISA was agreed.

15. De identified request for Information Manager (WSIC programme)

This proposal had already been discussed in detail at the DSA Sub-Group, but was brought to this meeting because the sub group had not been quorate.

KSa explained that they wanted to approve access for three information managers. It was for a range of uses and WSIC was the only source of this data. The managers are employed by ISA signatories. All the other CCGs who are signatories already have similar access and this would bring them into line. There is no patient-level data involved and they would only see de-identified data.

ACTION:

The GG agreed that it was a reasonable request. Given that it was already a recommendation from the DSA sub group (albeit non-quorate) it was agreed that it would be considered as Chair's action after the meeting and then reported to the next GG.

The Chair proposed that the meeting should end because it was not quorate and people were starting to leave. This was agreed and all outstanding items were moved to a future meeting. The meeting did not move to Part 2 and the work of the Dataflows, Security and Access sub-group. The Sub group minutes will be discussed at the next full sub-group meeting.

Agenda items for GG future meetings:

- Update on proposed changes for setting up accounts
- 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
- Update Risk Register