



**Digital North West London
Information Governance Group
Thursday 5th May
Time: 9.30-11.30**

*Venue: Ground Floor Boardroom, British Dental Association,
64 Wimpole Street, W1G 8YS*

Minutes

ATTENDEES

Name	Role	Organisation	IN.
Richard Baxter (Chair)	GP representative	Hounslow	RB
Alina Gritsenko	WSIC PMO	NWL Collaboration of CCGs	AGr
Amanda Lucas	WSIC Dashboards & DW Programme Manager	NWL Collaboration of CCGs	AL
Angeleca Silverside	Lay Partner	West London	AS
Anne Crofts	Partner	DAC Beechcrofts	AC
Araripe Garboggini	IG Manager	CNWL	AG
Ayub Pathan	IT Programme Manager	Harness Care	AP
Caroline Law	IG Manager	Chelsea and Westminster Hospital	CL
David Stone	IG Consultant	Kaleidoscope	DS
Janice Boucher	Borough Information Governance and Caldicott Support Manager	Triborough	JB
John Norton	Lay Partner	Central London	JN
Kate Glass	Network Manager	Kilburn GP Network	KG
Mohammed Al Ubaydli	CEO	Patients Know Best	MU
Muhammad Ali	IG Manager	Hounslow and Richmond Healthcare Trust	MA
Phillip Robinson	IG Manager	Imperial NHS Hospital Trust	PR
Raj Seedher	IG Manager	Brent Local Authority	RS
Sanjay Gautama	Caldicott Guardian	Imperial NHS Hospital Trust	SG
Selin Barnett	Digital Project Manager	NWL Collaboration of CCGs	SB
Sheri Ekladios	IG Manager	CLCH	SE
Simon Howarth	Deputy SIRO	London North West Healthcare NHS Trust	SH
Sonia Patel	Digital Programme Director	NWL Collaboration of CCGs	SP
Stephen Janering	Project manager- CIE	Imperial NHS trust	SJ



PART ONE: Provider Partners

1. Welcome and Introductions – Richard Baxter

- Welcomed every member to the inaugural meeting

2. Minutes and Actions – Richard Baxter

- The minutes of the 7th April 2016 meeting were reviewed and corrections to the minutes agreed.

ACTION UPDATE

PAUSED

#	Date	Action	Who	Update	Status
92	04.08.2015	Circulate National Partners Summary of WSIC Programme once available	SP	First draft was circulated for comment, waiting for LGA to write up case study. DS met with WELC who do not believe that IGA understand what we are doing nor do they think that they will publish material. SB to circulate link to recent publication. National work paused.	Paused
100	08.09.2015	RACIE of the proposed Programme to be shared with the Governance Group	JH	Paused until 2016.	Paused
101	08.09.2015	Imperial Healthcare Partners to come back to the Governance group to answer questions on data flows, IAO, Clarification of hand-off of liability (roles and responsibilities), patient complaints procedure and demonstration or proposal of look up tool.	JH	Paused until 2016.	Paused
103	08.09.2015	C2C team need to come back to Governance Group with feasibility data request	JH	Provider Partners have expressed concern.	Paused
126	03.12.2015	JC to get DPA's with TPP, System One.	JC	Following up, will be in place by March 2016. Ongoing	Paused
198	03.03.2016	SB ensure the Group is aware of the Change Academy and any other data sharing and access training opportunities	SB		Paused



OPEN/CLOSED

#	Date	Action	Who	Update	Status
52	04.05.2015	Process and procedures documents need to be updated and signed off by governance group Add terms and conditions onto user manuals	AL	On-going, more work needed by Data Processors. AL to bring back document to sign off.	Open
89	07.06.2015	Social Care Partners to provide agreed minimum dataset for the WSIC Data Warehouse	AL	Harrow - sent data. Brent - sent data. Triborough transferring soon. Still need Ealing, Hounslow, Hillingdon Councils to send list.	Open
164	04.02.2016	SB/SP to explore and understand the requirement for Royal Free to be part of Provider partners (paused till April)	AL	Further clarification around Royal Free is required. Consult with Anne Crofts.	Closed
166	04.02.2016	DS to share with the group paper on legal requirements to patient verification and citizen identity as discussed in the meeting with SG on 1 February	DS	Nothing has been submitted. Awaiting final approval. Bring to May meeting	Closed
173	04.02.2016	SP to bring back to the group mapping of the process for data requests sign off	SP	To be presented in June	Open
177	04.02.2016	SB and DS to work on audit templates	SB	To be presented in June	Open
178	04.02.2016	DS to test the audit templates with PR/RS/SH	DS	To be presented in June	Open
182	04.02.2016	AG/JC/SB to scope what will be appropriately to audit for partner providers and bring it March meeting	JC	April agenda. Risk register to provide overview which providers need support and where are the gaps. Bring back at June meeting	Open
199	07.04.2016	SB to ensure CIE consent engine demo is brought to May meeting (follow up from action #191)	SB		Closed
200	07.04.2016	PMO to review actions and amend as suggested	PMO		Closed
201	07.04.2016	JC/RH to provide report on GPs in NWL that have and haven't passed IGToolkit	JC/ RH	To be presented in June	Open
202	07.04.2016	JC to draft a response with RH reminding the practices that only practices with satisfactory for this year will have their data fed into dashboards. Share with SB for wider circulation once ready	JC	Summary report on exceptions would be beneficial. To be presented in June	Open
203	07.04.2016	ALL to send comments to SB to incorporate into next ToR to be published	ALL	SB to publish after the meeting	Closed
204	07.04.2016	SB to send out doodle poll to the Group to see availability of all for the future meetings	SB		Closed



205	07.04.2016	JC to clarify recommendation 7.2. from Incident Working Group action plan to RB	JC	To be presented in June	Open
206	07.04.2016	AL to keep Governance Group updated with progress of HSCIC data flows	AL		Closed
207	07.04.2016	AC to update ISA to reflect newly appointed Apollo Medical as sub-data processor for GP data	AC		Closed
208	07.04.2016	SJ to bring demo on the latest CIE programme progress to May meeting	SJ		Closed
209	07.04.2016	AS/JN/SJ to set up a meeting to discuss how the patients are recruited within the programme	AS/ JN/SJ		Closed
210	05.05.2016	SP to bring back assurance agreement, privacy policy and user acceptance agreement to this Group, for noting, in June	SP		Open
211	05.05.2016	AC to share the document on abbreviations and definitions as an addition to the ISA with the group	AC		Open
212	05.05.2016	ALL to provide their comments on the revised ISA within a week	ALL		Open
213	05.05.2016	SB to create FAQs and lay partner one-pager to be included at the front of the ISA, then circulate to the Group, together with the summary pack	SB		Open
214	05.05.2016	SB to confirm to the group when the Privacy Impact Assessment will take place following the formal adoption of CIE	SB		Open
215	05.05.2016	SB to send out CIE information and an official letter from the GG to the data controllers in common noting the change of ISA	SB		Open
216	05.05.2016	PAM to be brought back to July Governance Group meeting	SB		Open
217	05.05.2016	RB/AL to work together on re-writing the access rights for GPs for the access model	RB/ AL		Open
218	05.05.2016	RB/AL to hold a discussion with Royal Free on cross-border patients, exploring their principles and assumptions	RB/ AL		Open
219	05.05.2016	SB to add citizen accounts and verification to future meeting	SB		Open
220	05.05.2016	SB to add into ISA: 1) a requirement of the organisation to be CQC registered; 2) Apollo needs relating to all sub data processors	SB		Open
221	05.05.2016	AL/JC to bring penetration test from SECSU for discussion at the next meeting	AL/ J C		Open
222	05.05.2016	AL/SJ to meet to work up joint narrative for care staff and patients ref CIE and WSIC Dashboards	AL/ S J		Open



223	05.05.2016	PR to share the Google and Royal Free draft data sharing agreement with the Group	PR		Open
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3. Information Sharing Agreement - Anne Crofts

- PKB

- **SP** has explained the purpose of ISA and touched on all of the work that has gone into its development to incorporate both WSIC and CIE into one agreement. Data processing agreement sign-off will follow up in June by Brent Exec committee. The assurance agreement, privacy policy and user acceptance agreement will all also come back to this Group, for noting, in June.
- **AC** updated on the major structural change of the ISA which was making it more generic and including a set of principles. the latest ISA re-draft all on the key fundamental changes that have been agreed to date and explained the part a and part b within the agreement. **AC** added that there are separate schedules as an addition to the ISA and the first one contains abbreviations and definitions which she will share with the Group for clarity. **SB** mentioned that there is a section on FAQs which can be shared and a separate supplementary one-pager of terms and definitions for lay partners to be created.
- **SB** explained that CIE and Whole Systems Dashboard have been collectively referred to in ISA as Integrated Care Record for the ease of use and understanding.
- **SB** added that she will be sending round CIE information and an official letter from the GG to the data controllers in common noting the change of ISA.
- **SG** highlighted the issue of liability of clinicians accessing the data; e.g. clinicians may change the delivery of their care depending on the information available in the dashboard.
- **DC** clarified that the dashboard is a record made on behalf of a healthcare professional; hence it is not a health record, to which **SP** added that the information may be used differently when it interfaces dynamically through Master Patient Index into CIE.
- **DC** added that whenever the decision is made, clinicians need to reference it within the patient's record, as there are currently no mechanisms for snapshotting the information across the records for record keeping.
- **SG** noted that clinicians will note what they have done but not necessarily the information sources influencing that decision.
- **DC** added that clinicians may put themselves at risk if the information is available to them and they do not use it.
- **SG** highlighted the necessity of fast tracking the sign off process and proposed to use the June meeting for these purposes.
- **RS** asked if all of the supplementary documents and appendices will be included in the summary pack which is to be sent out to the Group, which **SB** confirmed.
- **SH** highlighted the confusion between the terms DPA and IPA being used interchangeably.
- **DS** asked if the Privacy Impact Assessment has been carried out for CIE, to which **SB** responded that it is to be done following the formal adoption of CIE protocols.

ACTIONS

- **SP** to bring back assurance agreement, privacy policy and user acceptance agreement to this Group, for noting, in June.
- **AC** to share the document on abbreviations and definitions as an addition to the ISA with the group
- **ALL** to provide their comments on the revised ISA within a week
- **SB** to create FAQs and lay partner one-pager to be included at the front of the ISA, then circulate to the Group, together with the summary pack



- **SB** to confirm to the group when the Privacy Impact Assessment will take place following the formal adoption of CIE
- **SB** to send out CIE information and an official letter from the GG to the data controllers in common noting the change of ISA

PART TWO: Innovation

4. Patient Activation Measurement

- Item carried over as PAM team were unable to attend

ACTION

- PAM to be brought back to July Governance Group meeting

PART THREE: WSIC

5. WSIC Dashboards Programme Update – Amanda Lucas

- Programme Update
- GP Data Update
- Data Requests
- Penetration Test from SECSU
- Out-of-area providers
- **AS** updated on the latest stages of dashboard deployment. Apollo has set up a portal for the practices to give electronic consent to data sharing with Apollo which in turn triggers data extraction. So far the practices sign up has been slower than anticipated. The workshop has been held with each of the Boroughs on how to show and represented adult social data within the dashboards. Currently the team is working only with the Brent data, as Tri-borough data is yet to be received. Automated data flow and access model are current challenges for the team. **AS** highlighted the need to define levels of access for GP providers within the access model, to which **RB** agreed to give a steer.
- **SG** highlighted that there are mechanisms in place for managing authenticated access.
- **DS** questioned the legitimisation of viewing multiple patients in a single view vs. single patient in a single view.
- **RB** mentioned that it is easier for this to be trialled in a hospital setting, and this should be the initial starting point.
- **RB** agreed with **AL**'s point on the need of patient search functionality and enabling different dashboard for different services. He emphasised that currently there is no coding structure around the patient discharge.
- **AL** updated on the local authority data sharing and the current debate around the level of access social care professionals should have. Lessons learnt from the CIE workshops would be highly advantageous.
- **AC** mentioned that there are currently the same issues for in-area providers as for the out-of-area providers around the data flows and the signatories to the ISA. This is when communication around where the data is coming from is important.
- **DS** mentioned that through PKB patients can invite other non-signatory clinicians to access the patient data. They cannot instruct as data controllers would but they have a statutory duty to share their data with the Royal Free, despite Royal Free communicating their data with Google.
- **SE** said that there are questions around Royal Free data flow to be answered: do they want to access the information and how many individuals need access. There is also a



consideration between Royal Free's engagements with Google, which will have an impact on the data sharing arrangements. **KG** mentioned the sub-contract on Integrated Care delivery and an access to the dashboard is required which means that the ISA most likely will need to be signed.

- **SP** added that if there are only a select few that need access, then there are arrangements that can be made around it. Otherwise adding additional signatories to the ISA is equivalent to additional signatories to the whole set up of NWL Digital Group, not simply to WSIC dashboard.
- **DS** said that Royal Free is a good example to show cross-borders patient flows, and a set of principles can be developed from that and applied to other providers.
- **DS** mentioned that in the previous meetings' discussions one of the principles of the signatories to the ISA was that the organisation had to be CQC registered, which **AC** confirmed.
- **AS** raised her concerns about data sharing outside of the organisation without the prior consent, with **SB** confirming that the data is view-only data and a section on this is included within the ISA.

ACTIONS

- **RB/AL** to work together on re-writing the access rights for GPs for the access model
- **RB/AL** to hold a discussion with Royal Free on cross-border patients, exploring their principles and assumptions
- **SB** to add citizen accounts and verification to future meeting
- **SB** to add into ISA: 1) a requirement of the organisation to be CQC registered; 2) Apollo needs relating to all sub data processors
- **AL/JC** to bring penetration test from SECSU for discussion at the next meeting

6. Update on HSCIC Engagement; WSIC Data flows – Amanda Lucas

- **AL** mentioned that the original ask from Brent was to load in the commissioning data set that was insecure with actions to talk to Royal Free if the access is required and to decide what access they may need.
- **DS** said that some regard to pan-London model of Integration and Integration engines needs to be given, considering the new scope of the Group.
- **AL** continued that the permission needs to be given to load in the Royal Free data for all NWL patients, pausing on any other providers as those have not had any specific requests.
- **DS** highlighted that the out-of-area data which comes out of the central resource is what the permission to load from HSCIC is needed for, unless it is a direct feed from Royal Free.
- **SB** updated that AL are asking HSCIC on two things: providing the data pack for direct care for secondary purposes and using providers for direct care basis.
- **RB** added that for Brent purposes, until HSCIC gives its permission, a direct feed is needed.
- **SG** asked if currently we can receive direct feeds from providers, with **AL** responding that it has not yet been set up. **RB** emphasised that it should be strongly approached.
- **RS** asked if there are any pre-requisites for a direct feed, to which **AL** replied that it has been already covered within other data packs.

7. Dissenting Patients – Amanda Lucas

- **AL** updated the paper from the previous meeting with the principles and brought it to this month's meeting for the Group to note.
- **AL** briefly touched on this as part of the programme update.



PART FOUR: CIE

9. Programme Update - Stephen Janering

- **SJ** briefly updated the Group on the deployment plan, and answered a few questions on simultaneous deployment of WSIC dashboard and CIE
- **AL** requested to meet with CIE so there could be a joint NWL narrative about the different integrated care systems on offer so that provider partners and patients don't get confused between the capabilities of WSIC dashboards and CIE

ACTION

- **AL/SJ** to meet to work up joint narrative for care staff and patients ref CIE and WSIC Dashboards

10. Live CIE Demonstration - Mohammad Al-Ubaydli

- **MU** walked the Group through the website from both views - patient and professional
- **AS** asked on the decision makers for the patient's results sharing, to which **MU** responded that the decision lies with the clinicians.
- **SG** mentioned that currently there is a delay of 4 weeks, to ensure that clinicians to have the right level of conversations with their patients and GPs regarding what the results will mean, and that there is a transparency between the clinicians and the patients.
- **MU** talked through the Integrated Care record plan on the website, which can be added by any user. The system has been designed for everyone to be able to add to the record, creating a full visibility of who added which information and when.
- **MU** showed how patients can view and amend what access and how much access each care provider has to their records. Each provider can establish their own ways of communication with the patients, depending on the particular interest to the provider.
- **DS** asked after PKB's remit of secondary use; secondary care systems have to be capable of recording this without relying on GPs, to which **SG** added that in this PKB becomes a consent engine and can be exposed to all partners.
- **SP** highlighted that if the sharing preferences are to be made transferable between all partners; it needs to be made clear to patients from the onset.
- **SG** said that currently there is no fair processing selective information sharing available.
- **DS** asked if the clinicians receive a notification each time the care plan has changed, to which **MU** responded that currently that functionality is disabled.
- **AS** asked if there is a section in the ISA on remote working and if there is a need for it, to which **SB** confirmed that the provider partners will have their own report access security and PKB has an encrypted data warehouse so patient information is secure and there is no need to cover this in the ISA

11. AOB

- **SG** mentioned the newspaper article in the guardian on Royal Free's acute injury alert venture with Google. He highlighted the anxieties around the Google Deepmind which is offering mobility and apps management, medical staff can task manage its patients within the hospital. Despite the move towards the electronic record holding, the doctors and nurses still use the paper forms for their daily task lists good opportunity for those working in the acute environment to be completely paperless, however acknowledges the fears of personal data from patients being shared with Google and the article.



- **DC** emphasised that what is reported in the article is wrong, and it is unknown whether it has been reported inaccurately by the newspaper.
- **PR** noted that the Goggle agreement states that the Royal Free remains as the data controller with Google acting on behalf of it.
- There was a group discussion around innovation versus safe sharing of information and the legal agreements to support. PR offered to share the royal free and Google data sharing agreement with group that is online.

ACTION

- **PR** to share the Google and Royal Free draft data sharing agreement with the Group