



**Digital North West London
Information Governance Group
Thursday 3rd November 2016
Time: 9.15-12.00**

***Venue: Room 5.1 and 5.2, 15 Marylebone Road,
NW1 5JD***

Minutes

ATTENDEES

Name	Role	Organisation	IN.
Amanda Lucas	WSIC Dashboards Programme Manager	NWL Collaboration of CCGs	AL
Angeleca Silverside	Lay Partner	West London	AS
Araripe Garboggini	IG Manager	CNWL	AG
Caroline Law	Head of IG	ChelWest/WestMid	CL
David Stone	Consultant	Kaleidoscope Consultants	DS
David Granger	IG Manager	Patient Knows Best	DG
Gilbert George	Head of Governance	Brent CCG	GG
Ian Riley	Director of Business Intelligence	NWL Collaboration of CCGs	IR
Iain Purves	Project Manager	WLMHT	IP
John Norton	Lay Partner	Central London	JN
Janice Boucher	Caldicott Support	Triborough	JB
Jo Andrews	IG Manager	North West London Healthcare Trust	JA
Laurie Slater	GP IT Lead	Hammersmith and Fulham CCG	LS
Nilesh Bharakhada	GP	Hillingdon CCG	NB
Philip Robinson	IG Manager	Imperial Hospital	PR
Ritu Shama	IG Manager	The Hillingdon Hospital	RSh
Saira Arif	Project Support Officer	Digital NWL Programme	SA
Selin Barnett	Digital Project Manager	NWL Collaboration of CCGs	SB
Sonia Patel (CHAIR)	Digital Programme Director	NWL Collaboration of CCGs	SP
Stephen Janering	Project Manager - CIE	Imperial NHS Trust	SJ
Tony Willis	GP IT lead	Hammersmith & Fulham CCG	TW
Fred Gregory	IG Manager	CLCH	FG
Jacqui Sinclair	Interim IG Manager	BHH	JS

PART ONE: Governance





1. Welcome and Introductions –

- Welcomed every member to the meeting

2. Minutes and Actions – Selin Barnett

- The minutes of the 6th October 2016 meeting were reviewed and agreed.

ACTION UPDATE

PAUSED

#	Date	Action	Who	Update	Status
100	08.09.2015	RACIE of the proposed Programme to be shared with the Governance Group	JH	Paused until 2016.	Paused
259	07.07.2016	SJ to email SP asking what the patient opt out process should be	SJ/SP	Once C3 signed off, bring to December.	Paused
277	01.09.16	joint letter with LLMC to GP's end of October	SJ/SP	Finalising revisions to comments from LLMC on Digital ISA before proceeding	Paused
230	07.07.2016	Adoption and sign off of the ISA needs to be reviewed in relation to Caldicott 3	SB	ISA adopted, to be taken back to legal advisors. Caldicott 3 not signed from DoH yet.	Paused
251	07.07.2016	Align version 2 of WISC communication documents to CWHEE MOU and CIE	AL	As part of sub-group	Paused

OPEN/CLOSED

#	Date	Action	Who	Update	Status
210	05.05.2016	Bring back assurance agreement, privacy policy and user acceptance agreement to this Group, for noting, in June	SJ MA	Comments have all been compiled together, further discussion needed. Timelines needed for further CIE progression.	Open
218	05.05.2016	RB/AL to hold a discussion with Royal Free on cross-border patients, exploring their principles and assumptions	SB/S P	Royal Brompton & Harefield are on the Digital footprint so process should be accelerated to get them signed up. Royal Free is in the plan already.	Closed
221	05.05.2016	AL/JC to bring penetration test from SECSU for discussion at the next meeting	AL/J C	Test done, outcome looking positive.	In progress
232	07.07.2016	The PIA to be updated and signed off by October	SB	SP and SG to discuss ownership of PIA for programmes	closed
236	07.07.2016	SB/SP to engage with LLMC on the new version of the ISA	SB/ SP	Update on agenda, in progress	Open
248	07.07.2016	AL to articulate what other data sets are required for on-boarding of data for WSIC	AL	On-going. To be picked up in sub group.	Open



		over next 6 months			
250	07.07.2016	WISC dashboards: Kaleidoscope commissioned and process procedure to be bought back to the Governance Group	AL	Copy of later action	Closed
254	07.07.2016	Hounslow and Ealing council to send data to WISC Data warehouse	RB	Richard Baxter to take up with Hounslow Joint Care Board	Open
261	07.07.2016	SB/SJ to explore on-boarding of urgent care providers, third party and out of area providers and add to agenda for future meeting	SJ/ SB	Sub group action- 25/11/16	Open
264	07.07.2016	RB requested more primary care participation within the group	SB	On-going	Open
279	01.09.16	One pager on Digital NWL Programme as standing item on agenda	SB	Bring to November meeting.	Open
281	01.09.16	Update from the pilot CIE GP practices for the next meeting (October)	SJ	Carried over – Pending IG	Open
282	01.09.16	AL to bring back update on the user case for secondary care for the WSIC Dashboards	AL	Finalising cases with clinical advisory group	Open
283	06.10.16	Sub Group for Access and Security to be set up – substantial item on agenda to include discussions around bringing in other partner providers	SB	Set up for 25 th November.	Closed
284	06.10.16	GG to supply a template to record risks, decisions and actions	GG	Will be discussed in December	Closed
285	06.10.16	Protocol to mention what is and what isn't an incident, needs more work around the definitions and levels	All	To be discussed in sub group	Open
286	06.10.16	The protocol to go to the Security, Access and Security Committee for further comment, to be signed off in December	All		Open
287	06.10.16	The following providers to test Data Controller Console: Philip from Imperial, Chelwest, Jo from LNW, Janice from TriBorough Social Care; Richard and Laurie to undertake beta testing. Digital Team to set up.	Digital Team	12 th Dec user testing group, Beta Version	Open
288	06.10.16	PKB to confirm timeline for development of the GP data filter as mentioned in previous meeting.	DG		Open
289	06.10.16	Kaleidoscope to update on development of Operating Manual for the WSIC dashboards.- For separate discussion on the agenda of the Governing Group	DS	December agenda	Open
290	06.10.16	AL to bring back to the group, the drafted paper which Kaleidoscope will review – this will help explain how different providers/systems access the data.	AL		Open



291	06.10.16	RS to liaise with SB and provide ideas / methodologies used around PIA	RS		Open
292	06.10.16	Kaleidoscope to liaise with SB ref the operating manual to make sure it is aligned with current Gov. Group documents. DS to bring update to future agenda	DS		Open
293	06.10.16	To set date for access and security Sub groups who will be the operational arm of the IG Group.	SB	Tabled for 25 th November	Closed
294	06.10.16	Agreed that discussions around bringing in other partner providers needs to be put as an item on agenda for the Sub Group for Access and Security.	Digital		Open
295	06.10.16	SG and SP to discuss further the question around funding of PIA as there are 2 hosts of 2 systems on the same ISA.	SG/SP		Open
296	06.10.16	DS to provide feedback and comments on Governance Group TOR to SB	DS	Published on website	Closed
297	06.10.16	SB to work with GG and Programmes to prepare paper on risks and issues for next meeting.	SB/GG	SB sent risks and issues to GG, awaiting response. On agenda for Dec meeting. Programmes to also input.	Open
298	06.10.16	Set up a Controls Table identifying what the controls are for WSIC Dashboard- RS.	RS		Open
299	06.10.16	LS to bring back to MOU once adopted and proposal for aligning governance groups.	LS	MOU GG set up for 2th Nov. tabled for Dec agenda	Open
300	06.10.16	Set up two DCC user groups for larger providers and GPs	SB		Closed
301	06.10.16	Symphonic to provide demo for the Tri-borough local authority IG meeting.	Digital		Closed
302	06.10.16	Find out who the Caldicott Guardian is for Royal Brompton & Harefield Hospital	SB		Open
303	06.10.16	SB to liaise with SJ about going out to Harefield and Royal Brompton with CIE to get them on board.	SB/SJ		Open
304	06.10.16	CMC to be invited to Future IG Group to understand the processes and design principles adopted by the IG Group. (LS) Invite to January Meeting.	Digital		Open
305	06.10.16	THH Data controller to be notified of the data request	SB		Closed
306	03.11.16	To add following substantive item to next meeting's agenda: ACP development and ISA	SB		Open





307	03.11.16	HLP to bring back roll out plan of DCC in December when they attend	HLP		Open
308	03.11.16	AS to provide group with User Matrix example	AS		Open
309	03.11.16	SJ to keep Register of PIO but shared with Gov. Group	SJ		Open
311	03.11.16	Sub group to be set up to work with SJ-NB/LS/Katrina Smith to be part of a discussion around sharing of mental health records.	Digital		Open
313	03.11.16	Update Incident Protocol to show that Partner providers incidents relate to are made aware	SB		Open
314	03.11.16	DG to send information the CL about PKB incident ref Chel West	DG		Open
315	03.11.16	DG to provide a formal letter from PKB with assurances that issues are being resolved and things are in place.	DG		Open
316	03.11.16	DG to share NCRS blog link with group	DG		Open
318	03.11.16	DE identified data request and children's data request to be resubmitted with proposed changes	AL		Open
319	03.11.16	Six monthly plan for WSIC dashboards needed to help with organising sub groups	AL		Open
320	03.11.16	WSIC dashboards team to update the data access request form, send to Governance group,	AL		Open
321	03.11.16	AL, conformation to group that the children's data asked for is same as adult data requirements. Specifically noted around children's mental health data and bring back to the group	AL		Open
322	03.11.16	AL and team to collect the names of the various Information Asset Owners for each provider as they progress. These names and details to be then held by the Governing group.	AL		Open
323	03.11.16	Bring back proposed Children's data set for group to review as part of data collection	AL		Open
324	03.11.16	AL to bring back user cases of children's data usage before collection for more than H&F area	Al		Open
325	03.11.16	AL and Tiffany to collect the names of the various Information Asset Owners for			



		each provider as they progress. These names and details to be then held by the Governing group.			
326	03.11.16	ACP to be an item on agenda for next meeting.			

- Minutes from October passed
- SJ requested clarification on signing up new providers to the ISA. It was noted by the group to proceed with Royal Brompton and Harefield as they are in the Digital footprint so ISA can be accelerated to them.
- SJ confirmed that Royal Brompton have been given a copy of the ISA, which they are currently reviewing.
- Penetration testing of WSIC Data warehouse done – to be added to the data access workshop established on 25th November for sign off
- PR Questioned whether review of ISA was going to be done to extend it out to make best use of the system – the idea was convert that into an overarching agreement. SB confirmed that we have spoken to legal advisors and they have advised ISA was not the right route because it is too specified around integrated care however the NWL ISP and the HLP Data controller console. We are also progressing with LMC, once these things are done, we will be in better position to see where the final ISA sits. ISP will be explored at next month's meeting.
- PR, emphasised that there is no need for multiple agreements; agreed that only one overarching agreement is really needed.
- SP gave an update on the LMC development and the on-going discussions. As part of the adoption of the CIE, technically and legally the CIE has been adopted into the digital ISA arrangements but still need to do rounds with LMC. Conversations and dialogue started around end of August. We feel confident that we have closed down all the assurances that the LMC have asked for and we pressed for them to progress the joint statement that we need to take for next stages. For clarity, the CIE can function with our major providers as the affiliation with LMC is not there. So exchange of information between our major partner providers can continue and start if it has not started.
- Inviting caldicott guardians (CGs) to this meeting – GG suggested there is no particular need to invite caldicott guardians unless there is specific item on the agenda which their input is needed for. SP suggested that CG's should be kept informed of the meetings via GG.
- SP updated the group on the presentation of the Data Controller Console (DCC) by HLP. It has some potential on how it could support IG staff but also help data controllers and data processors. It is beneficial even if it is just to be used as a repository of all the ISA's. Some individuals have undertaken the user testing, and this is currently progressing. This is currently behind schedule but they have proposed NEL to get their agreements out first.
- Group agreed that it is a good tool to group together all the ISA's in once place however some concerns raised when HLP stated patients would be able to tweak documents and have access to.





- SP clarified that as sponsor she has stripped this capability completely and the tool will be used as a document repository/ registry to enable sign up etc.

Action: SP proposed a substantive item on ACP development and ISA at the next meeting.

Action: HLP to bring back roll out plan of DCC in December

PART TWO: Strategy and Innovation

3. Patient Verification & Identification (Part One) – Stephen Janering

- SJ, Looking at whether current patient verification and identification is an acceptable level of identity or not. Current process is face to face whereby patient has to show photo ID (passport/ Drivers license): Other photo ID accompanied by a clinic letter presented on a corresponding date and time or appointment text; Record patient consent; Record email address; Provide information sheets
- Question around potential use of outpatient kiosks and whether this is acceptable. DS said currently it is not acceptable from a legal or national point. There is a standard GPG45 which is the GP online verification, it won't meet the civil legal, or criminal legal standard. The NHS is adopting a standard that is half way between level 2 and level 3 which would be difficult. Because we are giving PKB access to clinical data from their records, it doesn't meet the requirement standard of authentication. For overseas patients there will be a verification standard. For patient online, there is a patient authentication standard. Home office pushing NHS to authenticate patients more.
- RCGP have a whole procedure that they go through.
- There are more variations to face to face and online verification. DS happy to catch up with SJ.
- LS, Patients will want to know who is doing the authentication in GP Practices – Practice Manager.
- SJ, For GP's there is a set of guidance that they are required to follow for vouching and authentication of patient identity.
- Discussion around future process: Self check-in kiosk captured email addresses; already several thousand email addresses captured at Imperial. Question around whether these email addresses can be used in future.
- SJ, Long term vision is to Integration with Verify, which will be on the future agenda
- Joint proposal being prepared with Healthy London Partnership and NHS Digital
- Decisions being made:
 - Continuing with face to face model for on boarding of patients which works well for CIE for patients using the dashboard.
 - Create a standard arrangement for staff verification which is the RA model.
- Additional consent questions (in addition to record sharing preferences) to be asked at NWL Regional level or organisational level. Consent to contact by email, post, text; Consent to contact for audit; Consent to contact for research; Consent to storage and study of blood samples- Should these questions be asked once at a NWL regional level, or once per organisation?
- Consent to contact by email – discussion around if organisation contacts you or PKB, linked organisations? Wording constraint- needs clarity.
- Consenting around research – SJ to compare notes with DS as he has done some work on this.



- Blood samples consent – have different set of laws around it- will need to check the legal standing around this around obtaining consent online.
- Decision: to disable those options which CIE are currently being used.
- Action/ recommendation: to switch off those options until further discussions had, unless PKB can provide assurances that have been worked through.

Action: AS to provide group with User Matrix example

Action: Disable those options which CIE are currently using. Recommendation to switch off those consent/contact options until further discussions had, unless PKB can provide assurances that have been worked through.

PART THREE: Programmes

4. Care Information Exchange (CIE) – Stephen Janering

Programme Update

- SJ, haven't gone live with any of the GP early adopters, still waiting for LMC agreement. Testing feedback required by some users. At Imperial – now created over 350k records. Patient feedback- 70% response saying yes of those who are actively asked to sign up. People do seem to be positive about it.
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- Would be interesting to see if there's a different value perceived by the patient by service to see the return investment.
- Group discussion around how patients are signed up and approached. Active process involving resources such as admin teams and clinic teams.
- SJ confirmed that the CIE are looking at alternative ways to approach patients – not all patients are text savvy. Concern is that most vulnerable patients are not able to text. Alternative way to put information on patient letters for that part of population who do not rely on phones/text.
- Discussion around the way the CIE categorises the data and identifies the source – currently done through read or local codes but needs some direction on medication coding.

Mental health data

- SJ expressed some options to enable general health data from mental health data – how to identify the source without it linking back to mental health.
- Clinicians would want to know the source so they can make decisions on what to prescribe.
- Considerations need to be taken with certain medications due to the interactions/ side effects. (Re mental health drugs) Current process- letters sent to clinicians which discloses all this information
- Discussion around hiding mental health data – suggestions around testing this with a small group of mental health patients/users to obtain their input. CIE – current sharing is premised on implied consent. Caldicott 3 will need to be considered too.
- IP - If patients don't want to share their mental health records or sexual health records then suggested they opt out of CIE which is an option.
- Clinicians would need to know what the source of the information is. CIE data – not just primary care data, need to think about other sources of data.
- SB noted that the ISA involves two parts; first part is around data flows- visibility and access will be centred on patient access.



- SP, suggested that there needs to be a separate discussion needed on mental health data sets – looking at the source of information, or information relating to mental health. Digital Programme PMO will be able to help organise
- JN – concerns around patients having freedom to remove/exclude certain records pertaining to mental health. Could be potentially dangerous.
- Agreement from group that PKB data should remain categorised in their consent preferences as this put onus on patient. Patients have already agreed to share, so if they selectively choose to remove information that will be patient's choice.
- SJ confirmed CIE will send all medications as general and let patients categorise as they want to. Agreed by the group.

Network Access

- – By default, a professional can search and find patient who has been added to their team, as well as search for patient on their network. Professional has to justify access as to why patient being accessed. LS raised that this level of complexity is not manageable. Consider taking a simpler approach, where patients are asked what they want to see.
- DS suggested getting reports of the governing group once a month where the group is “breaking the glass”.
- SB, There is a need for “privacy impact officer” to be further defined and CIE as a programme. As providers are on boarded to PKB, they need to nominate a PIO. Register needs to be kept by CIE team but shared with this group.
- IP suggested we do not need an opt out that applies to all organisations. Currently we have the ability for any organisation to see the data and then have patient to step in before or after and essentially opt out. (Katrina to approve this within her organisation).

Action: Sub group to be set up to work with SJ- NB/LS/Katrina Smith to be part of a discussion around sharing of mental health records.

Action SJ to keep Register of PIO but shared with Gov Group

5. PKB – David Grange

- Since beginning of year, these are the only two incidents so far nationally in PKB.
- SB noted that the report has been signed off by Raj Seedhar before being presented to the group as per the security protocol
- Incident 1 that relates to Imperial - Record created for patient A, whilst it was created there was a manual key error which added patient B's information. A and B are related. Patient B declined PKB account. Patient A was given PKB account. Patient A logged into account and noticed demographic data was incorrect. Data related to patient A not B. Incident was reported. Data was secured. Patient A had seen B's data (father). Within 2 hours, data was secure. Further went on to remove data. Remedial steps. Patients were informed all the way through. Report was given to royal Liverpool and AKU.
- Concern was by PR who has not been involved. No one interacted with Imperial Data Protection (Philip). The process clearly bypassed PR and went straight to Raj. Need to be careful – in future, data protection officer need to be notified. SJ has full report if members need
- SB noted that we will update the security protocol to reflect notification of provider partner of any future incidents





- Lessons learned: Now flagging demographic data previously were not doing this. PKB are implementing full version control to audit trail which professional / coordinator made change. Multiple demographic field changes are now being flagged as verification. DOB changes are flagged, not blocked but a report will be compiled. Continual focus on PKB record creation protocol.
- Incident 2 relates to ChelWest test record which had a live NHS number- Imperial had written clinical information on test patient. Concern is that ChelWest data officer was not notified.
- NCRAS Cancer records: When patients register with PKB, they are checked against national cancer analysis database (NCRS), to see whether that service holds any information on any patients who have registered. December will be when integration takes place.
- PKB do not share information with the NCRS but provide the PKB patient to get information that national database holds. No data shared with cancer database at this point, it is a one way feed. As a follow up, patients are given option to consent to take part in cancer research. They don't have to take part, but can still get their information. If they do want to participate in research that point is where their information is shared with cancer database.
- Lay partners would ideally like to see those terms and conditions to vet them, should be part of the review of the PKB terms and conditions.
- Blog post contains the information of how much data is shared with NCRS.

Decision: Provider Partners are happy to add in NCRAS consent item to CIE record for NWL

Action: SB to update the security protocol to reflect notification of provider partner of any future incidents

Action: DG to send information the CL about PKB incident ref ChelWest

Action: DG to provide a formal letter from PKB with assurances that issues are being resolved and things are in place.

Action: DG to share NCRS blog link with group.

Action: Terms and conditions for sharing to be looked at by group. DG to provide.

6. WSIC Dashboards – Amanda Lucas/Tony Willis

Diabetes De-identified subject access request

- AI, Redesign of diabetes pathway for NWL service development. This is also a national priority and is being championed by NHS Right Care, STP, ACP, OOH. NWL is partnering with Department of Health to do costing model for diabetes
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- Discussion of why we need patient name, AI advised to take out.
- Query from group around whether the information was going to be re-identified or not, TW confirmed that this was not the case. SP, noted this needs to be reflected in the application –



Decision: Agreed by group to have scrambled NHS number, post code plus three. Need to resubmit form to group once changes have taken place

- Query on uptake of dashboards in H&F as information can only be collected for direct care, this needs to be a secondary purpose
- AL Focus is currently on H&F only because they have full data set however redesign will be across CWHEE.
- Future data request will go to Sub Group- frequency of sub groups yet to be decided but need to come to main GG to be signed off.

Collection request – Children’s data

- Paper is for better management of long term conditions for children in NWL, this would also be useful for MDT’s working with Imperial NHS trust.
- AL confirmed that this request was worked up with Peter Beard, commissioner on learning disabilities.
- SP enquired whether the children’s data was requested for just H&F or for the whole of NWL?
- AL noted that the data collection they would like to start with GP data sets first then add the large providers
- Laws for children data is different specifically around cMHMDS AL advised to check the legal points around it and come back to the group.
- Discussion around what the issue is around using SLAM/SUS data
- GG enquired who which area this data was being collected for as noted that this only says CWHHE but has H&F sponsor. It was noted that information can only be collected on a direct care basis, group suggested that this is worked through and be submitted on an area by area basis.
- AL enquired whether they could collect national data sets by area as well or can they do all of NWL in one go? Get sus and slam – but specify data sets.
- Recommendation by group: to work with one CCG/area and to get that data set defined and user cases for collection.
- Group would like WSIC dashboards team to resubmit Children’s data request once queries have been answered.

Principles of Access for non GP Provider Partners

- WSIC dashboard user access form provided to group
- Access to patient search – audit function and reporting available.
- Ensure that provider partners have appropriate arrangements in place to manage this.
- Each provider can be provided with regular reports. Spot checks can then be done on each provider system by the providers.
- Cannot audit the access at the moment – but further discussion can be done at sub group
- AL is request that the process being proposed is the right one for taking forward as would like to expedite Provider partners to get access these include: CNWL Hillingdon nurses, Brent Council team leaders, Imperial
- SP stated that dashboard team will need to ensure provider partners have appropriate process in place to be able to verify and maintain access.
- PR stated each provider partner should have a designated information asset owner.
- SP suggested therefore the Governing group maintain the details of the Information Asset Owners. Making sure the GG maintains a list of these asset owners.

Action: De-identified data request and children’s data request to be resubmitted with proposed changes

Action: Six monthly plan needed to help with organising sub groups- AL





Action: WSIC dashboards team to update the form, send to Governance group, who will review and send to Letter out to GPs from the Chairs. 2 week cycle.

Action: Bring back proposed Children’s data set for group to review as part of data collection

Action: AL, conformation to group that the children’s data asked for is same as adult data requirements. Specifically noted around children’s mental health data and bring back to the group.

Action: AL to bring back user cases of children’s data usage before collection for more than H&F area

Action: AL and Tiffany to collect the names of the various Information Asset Owners for each provider as they progress. These names and details to be then held by the Governing group.

7. AOB

Action: ACP to be an item on agenda for next meeting.

DECISION LOG

#	Date	Decision
001	03.11.16	Group agreed that it is a good tool to group together all the ISA’s in once place however some concerns raised when HLP stated patients would be able to tweak documents and have access to.
002	03.11.16	Recommendation to switch off those consent/contact options until further discussions had, unless PKB can provide assurances that have been worked through .
003	03.11.16	Continuing with face to face model for on boarding of patients which works well for CIE for patients using the dashboard.
004	03.11.16	Create a standard arrangement for staff verification which is the RA model
005	03.11.16	To disable those options which CIE are currently being used. To switch off those options until further discussions had, unless PKB can provide assurances that have been worked through.
006	03.11.16	Provider Partners are happy to add in NCRAS consent item to CIE record for NWL
007	03.11.16	Agreed by group to have scrambled NHS number, post code plus three. Need to resubmit form to group once changes have taken place