



**Digital North West London
Information Governance Group
Thursday 12th January 2017
Time: 14:00-17:00**

Venue: Upper Mews, British Dental Association, 64 Wimpole Street, W1G 8YS
Minutes

ATTENDEES

Name	Role	Organisation	IN.
Amanda Lucas	WSIC Dashboards Programme Manager	NWL Collaboration of CCGs	AL
Angeleca Silverside	Lay Partner	West London	AS
Caroline Kerby	Network Director	Harness GP Network	CK
Caroline Law	Head of IG	ChelWest/WestMid	CL
David Birkenshaw	Consultant	Kaleidoscope Consultants	DS
David Granger	IG Manager	Patient Knows Best	DG
Emma Cooper	Digital IG Lead	NWL Collaboration of CCGs	EC
Fred Gregory	IG Manager	CLCH	FG
John Norton	Lay Partner	Central London	JN
Janice Boucher	Caldicott Support	Triborough	JB
Laurie Slater	GP IT Lead	Hammersmith and Fulham CCG	LS
Muhammad Ali	IG Manager	HRCH	MA
Nilesh Bharakhada	GP	Hillingdon CCG	NB
Philip Robinson	IG Manager	Imperial Hospital	PR
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
Jacqui Sinclair	Interim IG Manager	BHH	JS

PART ONE: Governance

1. Welcome and Introductions –

- Welcomed every member to the meeting

2. Minutes and Actions

- The minutes of the 1st December 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	Discussed on agenda	In Progress
221	05.05.2016	AL/JC to bring penetration test from SECSU for discussion at the next meeting	AL/J C	Completed	Closed
248	07.072016	AL to articulate what other data sets are required for on-boarding of data for WSIC over next 6 months	AL	Advised once CAG meet.	Closed
261	07.072016	<i>SB/SJ to explore on-boarding of urgent care providers, third party and out of area providers and add to agenda for future meeting</i>	<i>SJ/ SB</i>	<i>Highlight report requested from sub group.</i>	<i>Sub group</i>
279	01.09.16	One pager on Digital NWL Programme as standing item on agenda	SB	Still working with comms team to develop what this will look like.	In Progress
282	01.09.16	AL to bring back update on the user case for secondary care for the WSIC Dashboards	AL	CAG	Closed
291	06.10.16	RS to liaise with SB and provide ideas / methodologies used around PIA	RS	To be taken offline for a discussion – EC to touch base with PR, proposal to be discussed in March.	In Progress
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/S P	In progress	In Progress
298	06.10.16	Set up a Controls Table identifying what the controls are for WSIC Dashboard- RS.	RS	To be picked up in April 2017	In Progress



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	EC has been invited to a CMC meeting in Feb, so this can be picked up in March agenda.	Open
308	03.11.16	AS to provide group with User Matrix example	AS	Done	Closed
309	03.11.16	SJ to keep Register of PIO but share with Gov. Group	SJ	Add to risk and issues log- take off the action register.	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	Picked up in sub group	Closed
318	03.11.16	DE identified data request and children's data request to be resubmitted with proposed changes	AL	De identified data request will be discussed at sub groups.	Closed
320	03.11.16	<i>WSIC dashboards team to update the data access request form, send to Governance group,</i>	AL	<i>Action in sub group</i>	<i>Closed</i>
323	03.11.16	Bring back proposed Children's data set for group to review as part of data collection	AL	Sub group	Closed
324	03.11.16	AL to bring back user cases of children's data usage before collection for more than H&F area	Al	Complete	Closed
327	01.12.16	More information requested on the costings on the DCC to be circulated as well as the user guides.	CM	NHSE have asked re costings.	Open
328	01.12.16	Amend scoring for each risk on risk register, modify changes suggested and re circulate risk register.	Digital	Completed, discussed on agenda.	Closed
329	01.12.16	Everyone to review the Incident Management protocol and provide comments.	All	Discussed on agenda	Closed
330	01.12.16	RS to think about TOR for new suggested operational group/ what to call it.	RS	Bring back to next meeting.	Open
331	01.12.16	TOR to be reviewed by all, comments to be provided to team.	All	Completed	Open
332	01.12.16	<i>Action: For sub group – include decision and recommendation log so it is clear to the IG group what is being sought approval.</i>		<i>Sub Group</i>	<i>Sub Group</i>
333	01.12.16	Invite Dawn from NHSE to future meeting.		Invited. Waiting for confirmation	



334	01.12.16	SP to look at the operating manual and have discussion with DS.	SP/D S	Discussed, David will split up into two parts, one for governing group and then one for dashboards team; and CIE.	Closed
335	12.01.17	Incident Management Protocol – agreed by group, to be published.	EC		Open
336	12.01.17	DG to produce the Incident protocol letter on letterheaded paper, send to EC for records.	DG,E C		Open
337	12.01.17	JN to work with DG to go over the revisions of the user agreements.	JN/D G		Open
338	12.01.17	DG to note that the definitions in agreement need to be pulled out and clear for patients to see and understand.	DG		Open
339	12.01.17	Social care data set request by CAG– to be reviewed within 2 week time frame.	AL		Open
340	12.01.17	Recommendation: Review Fair processing to help align with AL’s work. Also FP to include children.			Open

- Minutes from December passed.

LLMC Update- Sonia Patel

SP updated the group with regards to her discussions with LMC around progressing the Digital ISA. SP had a meeting with both Eleanor and Lesley around the signing of the joint statement, to which they have sent some amendments which were then sent back. Dr Nilesh Bharakhada has kindly offered to help iron out any issues.

The clear signal from Eleanor around re signature, is that whilst the dashboard team can continue based on the previous ISA, any material changes to the data or purpose will require re signature to the digital ISA.

This means however the current state of dashboards can continue to be delivered. Any additional functionality based on the same data set can continue to be delivered; any new data sets however will require a new signature and sign up to the digital ISA.

The reason why the original re signature is required is because of adoption of CIE.

If we are asking for any change request on the ISA, this group would have to maintain two data sets. LS, suggestion that this all needs to be communicated to GPs.

SB, ISA is future proofed, you cannot future proof data sets, only reason why LMC wants us to go out again for re signature is because it’s an adoption of a completely different line of work.

LS, The mitigation against this, the LMC will eventually be invited to this group so actively have to be included in the discussions.

SP, Future strategic meeting to be had with Eleanor and Lesley around our forward plans. Keen to work with LMC, agreed that it is something that takes time.

LMC keen on getting the DCC running as it will help the LMC to view the agreements electronically.



Incident Management- Emma Cooper

EC, minor changes that need to be adopted by group, circulated to all.

Language changed from “should” to “must” changed”.

Discussions to be had with how to follow the Incident protocol. So upcoming meeting scheduled with Jacqui and Amanda.

JN, suggested that “shall” is better than “must”.

Action Agreed: finalise and publish.

PKB – Incident Management Procedure – David Grange

DG, discussed letter outlining the process around the incident protocol management, and asked for comments.

Agreed that incident management protocol will be put on letter headed paper, sent to EC to be kept on file.

PR, asked where it indicates informing data controllers. All agreed that whatever happens, both parties need to be informed, ie. Host data processor (Brent), and the Data Controllers.

Action: DG to produce letter on letter headed paper to send to Emma who will keep on file for records.

PKB Privacy Statement for patients – John Norton

JN, raised points on user agreement through Michael Morton. Versions were shown in group. Agreement is extremely unfriendly to the user. How is this going to be implemented, by who, and when?

It was suggested that if this becomes binding on users, it will have to explain much more in detail, so that PKB can establish an agreement was made.

AS, spoke to PKB about JN comments. Concerns were that it’s not user friendly.

DG confirmed the comments were logged. In the documents that were distributed, there were total of 15 changes. Changes were not logged.

PKB lawyers have seen the documents, Beechcrofts have not seen the documents.

It will not be an agreement until the user can agree to its interpretation.

SP, it would be helpful for JN to spend time with DG from PKB looking at style and tone of the wording in the user agreements.

DG, the issue was that this has already gone through process of legal review, we are though establishing if its user friendly.

JN, how and by whom will the agreement be explained to patients so they have sufficient knowledge. What is the procedure for this.

DG, this is published on the website under the privacy statement, replaces what was agreed. The ones that are live on website, are the agreements in place.

PR, Are we mixing up the fair processing with the Terms and conditions- Because these are two separate things.



EC, what the ICO would be looking for is that the language is clear, easy read version of the agreement. Would be helpful to indicate the terms and conditions are different to the fair processing agreement.

AS, definitions are currently buried into document, they need to be pulled out and put on the side easy to see by patients.

JN, concerns that his comments and issues raised re user agreement months ago has been ignored.

Action: JN to work with DG to go over the revisions of the user agreements.

Action: DG to note that the definitions in agreement need to be pulled out and clear for patients to see and understand.

GDPR General Data Protection Regulations – Emma Cooper

GDPR framework adopted, which is coming through May 2018. The government has confirmed that regardless of Brexit that we are going to be subject to it. Contains some onerous obligations, which will take time to prepare for and will have an immediate impact.

Areas where there are changes:

Expanded Reach

- GDPR catches DCs and DP outside the EU whose processing activities relate to the offering of goods or services (even if for free) to, or monitoring the behaviour (within the EU) of, EU data subjects.
- Companies outside the EU with consumers in the EU will now be subject to GDPR.

Data Protection Officers

- A suitably qualified Data Protection Officer must be delegated where;
- Processing is carried out by a public authority
- Core activities of the DC or DP consist of processing which requires regular and systematic monitoring of data subjects on a large scale
- Core activities consist of processing on a large scale of special categories of data (sensitive data and now includes “genetic data” and “biometric data”

Privacy by Design

- GDPR places onerous obligations on DCs to evidence compliance.
- Maintain certain documentation (Art 30)
- Conduct PIAs for more risky processing (DPAs should list outcome)
- Implement data protection by design and by default, e.g. data minimisation.

Data Processors

- Data Processors have direct obligations for the first time;
- Document processing activities carried out on behalf DCs
- designate a DPO
- appoint a representative (when not established in the EU) in certain circumstances;
- Notify DC the DC of data breach without undue delay
- Cross border transfers also apply to DP, and BCRs for DP are formally recognised.
- New status of data DP likely to reflected in contractual arrangements

Consent



- A data subject's consent to processing of their personal data must be as easy to withdraw as to give consent.
- Consent must be "explicit" for sensitive data.
- The DC is required to be able to demonstrate that consent was given.
- Existing consents may still work, but only provided they meet the new conditions

Fair Processing

- DCs must continue to provide transparent information to data subjects.
- This must be done at the time the personal data is obtained
- Under GDPR, the FPN are more comprehensive

Data Breaches

- DCs must notify most data breaches to the DPA without undue delay and within 72 hours. Reasoned justification if not.
- If there is likely to be a "high risk" to their rights and freedoms, must also notify data subjects without undue delay.
- ICO already expects to be informed about all "serious" breaches.
- Under GDPR notification is only required if the breach is likely to result in a risk to the rights and freedoms of individuals.

Fines

- Introduces a tiered approach to penalties
- DPAs to impose fines for some breaches of up to 4% of annual worldwide turnover or EUR20 million (eg basic principles for processing, such as conditions for consent).
- Other specified contravention could result in a fine of up to 2% of annual worldwide turnover and EUR10m.
- Points to consider when imposing fines (such as the nature, gravity and duration of the infringement) is provided.

Notifications

- Removal of the requirement to notify or seek approval from the ICO in many circumstances.
- Instead a new requirement to consult the ICO in advance where a PIA indicates that processing would result in high risk unless measures are taken to mitigate that risk.
- If the ICO determines that the processing would breach GDPR, they can provide written advice and use enforcement.
- Means DC will have to assess the outcome of PIA and consider whether to consult with ICO

Data Subject Rights

- Strengthened rights include SAR, amendment of incorrect data, restriction for direct marketing
- Subjects can request data in a structured format so that it can easily be transferred to another DC ("data portability").
- "right to be forgotten" or "right of erasure". Individuals can require the DC to erase their data where they withdraw consent and no other legal ground for processing applies
- Must take reasonable steps to inform third parties about a request to erase any links to, or copies of, that data.
- DC must respond to these requests within a month, (possible to extend for complex requests)
- Need clear processes to meet these obligations. Should be free of charge unless the request is "manifestly unfounded or excessive".



- In regards to consent, we cannot come to any conclusions yet until more information around Caldecott 3.
- The data breaches need to be reported – not sure yet if ICO will release threshold to help you make that assessment whether its likely to be high risk breach or not.
- Regards to notifications, to be noted that they are removing the need to notify the ICO.
- LS, sharing records TPP, sharing in and out, we don't have Caldicott proportionality currently therefore relying on community.
- PR, discussion around how contracts will be affected by the preparation, a lot of work and time to go into this.
- EC, GDPR added to the risk register.
- LS, suggested it would be a good idea to get exemplars on the activities currently going on.
- the activities currently.

ACP Update – Emma Cooper

EC currently getting advice from Beechcrofts around questions they have. Still waiting to hear from them with questions.

Care Information Exchange (CIE)

SJ happy for group to review material and update in their own time. Slides provided to group.

CWHHE MOU Update – Dr Laurie Slater

- Meeting in November where the agenda there was to recognise that the MOU needs to be taken in context of the ISP, an overarching arrangement would be something MOU would sit under.
- Keen to recognise how we share information with social services, group felt we are still some way away from doing so in some mainstream way, however it was recognised that some good work has been underway around this.
- The group wanted to propose mechanisms to share with social care, making sure there are appropriate mechanisms to share, but there was a kick back from LMC.
- Would social care be able to view the whole record? LS, made the point that social workers are part of MDT, as long as there is explicit consent.
- LS, main concern is around sharing the whole record for social care.
- SP, suggestion Whole systems dashboards are the de facto tools to sharing out.
- LS, one of the concerns LMC had with CIS service – if patient do not give their consent for full service, then patient do not get the service.
- Another point LMC raised was GP to be granted indemnity for specific complaint being raised against them. If MOU can do this out of good faith.

WSIC Dashboards Update- Amanda Lucas

- Programme Update
 - GP data received from 177 practices (representing 66% of those practices who have signed ISAs). Accounts issued to 122 GP practices and 25 network staff across Hillingdon and West London.
 - Kicked off all practices with the exception of Ealing and Wave 3 in West London. Ealing and Wave 3 in West London have both agreed to kick off which amounts to an additional 97



practices, but are unable to proceed until the revised statement from London LMC is available.

- Release 8 has been deployed. This includes fixes and product enhancements prioritised by the Clinical Advisory Group, including a complete set of 41 Long Term Conditions, social care visualisation, and list maker enhancements.
 - Activity for NWL patients from the the top 5 out of area providers prioritised by the Clinical Advisory Group have been deployed in Release 8, this includes: Royal Free London NHS Foundation Trust, UCL NHS Foundation Trust, Moorfields Eye Hospital NHS Foundation Trust, Guy's & St, Thomas's NHS Foundation Trust and Ashford & St Peter's NHS Foundation Trust.
 - The Clinical Advisory Group has identified additional use cases for Long Term Condition specific watch lists. Work planned to scope a COPD radar and a children's patient radar.
 - Focus is moving towards the 'ACP or population health dashboard' as well as the on-going enhancement of the Care Professional Dashboard.
 - Team has identified a number of anomalies in SystmOne data from H&F and Hounslow CCGs. Investigations in conjunction with Apollo Medical have uncovered a likely cause, NWL working with Apollo to agree plan for resolution.
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- Access principles – Requests for de-identified data will go to sub group, but it was suggested to agree the Access Principles here at the IG group and then given to providers. Feedback asked for.
 - SP, caveat, need a process for de identified data set, but the LMC point out where the data set is looked at for GP services.
 - The sub group will review the data set requests, and will have to keep a log of them. **Sub group will need to create a log that is auditable– what data requests have come in, the log then needs to come to IG group for information only.**
 - Suggestion for sub group, once access is given, to monitor use of direct care use.
 - Noted that de identified data cannot be re identified.

- Social Care data Update

Data request from CAG – data social care review

SP, if social care is contributing data in, they should be able to receive things back. Agreed by group.

Action: Social care data set request by CAG– to be reviewed within 2 week time frame.

ISA Signatories Requests

Kilburn & Willesden- ISA request – Prashant

- Agreed that K&W had the specifics in place: ie. CQC, ICO and IG registration.

Group agreed to the ISA Request by K&W, with the requirement that representation by them will be needed at meetings regularly.

Harness ISA Request – Caroline Kerby

- CK, presented case for becoming ISA Signatory.
- Confirmed that Brent Care is a legal entity.



- Three networks within the legal entity are all working with level of data sharing.
- AS, who is having access to data, all three networks or Brent care? CK confirmed that Brent care currently doesn't employ anybody, sub contracted to each networks.
- Kilburn – work as a non profit.
- K&W – works by shares.
- Harness– non profit, social enterprise.
- Who are the data controllers: The three networks are data controllers. They have tool kits, GPs. Etc.
- Networks are delivering direct care services.
- SP, if accessing the data, they should be contributing- Confirmed that Brent are contributing data sets.

**Decision: Representation needed at IG Group
Harness and K&W networks agreed by group to be a ISA Signatory.
Both requests will go through the two week mechanism.
GP's to continue attending.**

Kilburn ISA Request – No representation at IG Group.

Childrens Data – Emma Cooper/Amanda Lucas

- EC, went through what is the consent model going to be for children and young people for that data.
- Ensure that fair processing notices are appropriate for children and young people.
- Ensure no linkage will be happening with social care and mental health data.
- Confirm there is no risk associated with the information being used not being contemporaneous.
- Consider if fair processing appropriate and legal
- Need to ensure Data Controller is happy
- Core elements could be provided for people to adopt
- We are asking for data controller to confirm their Fair Processing is appropriate for young people. – positive confirmation needed
- SP, Fair processing should be reviewed, should be lined up to include children to help AL and her team.
- Ensuring language used is children friendly – suggestion easy read notice
- Onus should be on data controller so risk is mitigated.

Recommendation: Review FP work immediately to include children.

AOB

SP, updated on NHSE producing the Interoperability Structure.

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
008	12.01.17	Sub group will need to create a log that is auditable– what data requests have come in, the log then needs to come to IG group for information only.
009	12.01.17	Group agreed to the ISA Request by K&W, with the requirement that representation by them will be needed at meetings regularly.
010	12.01.17	Decision: Harness and K&W networks agreed by group to be a ISA Signatory. Guarantee of Representation needed at IG Group by networks. Both requests will go through the two week mechanism. GP's to continue attending.