

WSIC ISA Governance Group: 8th September 2015

Attendance

Name	Role	Organisation	Attendance
Dr Aumran Tahir (chair)	Clinical Director WSIC Programme West London GP Representative	NWL Collaboration of CCGs	Yes
Kuldhir Johal	CCG GP IT Lead	Hillingdon CCG	No
Simon Howarth	Deputy SIRO	London North West Healthcare NHS Trust	Yes
Katrina Smith	IG Manager	West London Mental Health NHS Trust	No
Raj Seedher	IG Manager	Brent Local Authority	Yes
Alistair Robertson	Solicitor	DAC Beechcrofts	Yes
David Stone	IG Consultant	Kaledoscope	Yes
Sonia Patel	WSIC Informatics Lead	NWL Collaboration of CCGs	Yes
Selin Barnett	WSIC Project Manager	NWL Collaboration of CCGs	Yes
Angeleca Silverside	Lay Partner	West London	Yes
John Norton	Lay Partner	Central London	Yes
Mary Umrigar	IG Manager	Ealing Council	No
Caroline Kerby	GP representative	NHS Brent CCG/ Brent Harness Network	Deputise
Ritu Sharma	IG Manager	The Hillingdon Hospital NHS FT	Yes
Caroline Law	IG Manager	Chelsea and Westminster Hospital	Yes
Gary Wilsher	IG Manager	Hounslow Council	Deputise
Sanjay Gautama	Caldicott Guardian	Imperial Hospital NHS FT	No
Graham Trainor	IG Manager	West Middlesex University Hospital	Yes
Reena Parmar	IG Manager	Harrow Council	No
Phillip Robinson	IG Manager	Imperial Hospital	Yes
Jason Clarke	IG Manager	BHH- Brent Host	Yes
Rory Hill	IG Officer	CHWHHE	No
Stephen Murphy	IT Commissioning and Information Governance Specialist Adults Social Care Shared Services	Triborough	Yes
Janice Boucher	Borough Information Governance and Caldicott Support Manager	Triborough	No
Kate Glass	Project Manager	Kilburn GP Network	Yes
Vijay Patel	IG Representative	Harness GP Network	Yes
Sheri Ekladios	IG Manager	CLCH	Deputise

Simon Haines (deputy)	Analyst	Hounslow Council	Yes
Cyndee Massa (deputy)	IG Facilitator	CLCH	Yes

Presenters

Jess Henderson (JH)	Innovation Delivery Lead	Imperial College Health Partners
Adrian Bull (AB)	Managing Director	Imperial College Health Partners
Samia Hasan (SH)	C2C- GP Clinical Lead	Imperial College Health Partners
Barry Newton (BN)	Lay Partner Representative	Imperial College Health Partners

PART ONE: Governance & Updates

2. Minutes and Actions Update

- Minutes were agreed by the group

Action No.	Date	Action	Assigned to	Status/Update	Status
1	03.03.2015	AT to write to West London CCG, Brent CCG, Central London CCG about commitment to the group	AT	<p>Person identified from Central London however unable to attend on behalf of GPs as person does not represent data controllers, still open</p> <p>Programme Team meeting with CLH in October will ask for representative for Central London0- open new action</p>	Closed

52	04.05.2015	Process and procedures documents need to be updated and signed off by governance group	SB	<p>Ongoing, more work needed by Data Processors</p> <p>SB to send PKB DPA to PR to move forward</p>	Open
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64	04.06.2015	AR to define risk stratification in the PIA	AR	Risk stratification focus group to work through definition set up end of September Put on agenda in October	Closed
68	04.06.2015	ISA Governance Group to send letters to the CCGs to ask for them to encourage the GPs that have not passed the IGT in March but have signed the ISA letters, to ask them to be compliant and confirm.	JN	Paused	Paused
69	04.06.2015	Governance Group members review and feed into the Communication & Engagement Strategy by July Governance Group.	All	Working Group set up and will bring back to group in September On Agenda	Closed
70	04.06.2015	Explore Tier, for an independent reviews of security arrangements and provide feedback to the governance group.	SP	SP to bring back to group in October after Data Warehouse is operational	Paused
73	04.06.2015	JN and AS to ask their LPAG colleagues to support a joint letter to Simon Stevens to improve TPP system for the benefit of the patients	JN/AS	Update at meeting in July	Paused
75	04.06.2015	SG to bring back formal briefing in July to group on CIE and how the Information Governance would fit together	SG	Programme team will try and get on October Agenda	Open
83	07.06.2015	Update Governance Group on LLMC meeting about data sharing	SP/SB	Meeting with LLMC 25th August. SP to report back at September meeting Feedback on Agenda; We have agreed a joint statement with the LLMC to support the WSIC ISA	Closed
84	07.06.2015	Bring Data Processing Agreement back to Governance Group in August	SB	Concentra DPA shared at meeting. Will bring back other 3 DPA's in September Brent CCG (Host) Exec Group are yet to sign off DPA's, update on agenda (Sept)	Open

87	07.06.2015	Governance Group would like a youtube video to be circulated to the governance group to show full capabilities of PKB platform	SB	Required as part of next update	Open
89	07.06.2015	Social Care Partners to provide agreed minimum dataset for the WSIC Data Warehouse	All	Harrow Sent data Brent Sent data Meeting set up with Triborough	Open
90	04.08.2015	Bring back Communication material in September	SB	On agenda	Closed
91	04.08.2015	Bring back Terms of Reference in September	AR	On agenda	Closed
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	Open
93	04.08.2015	Bring back all DPA's once Brent Governing Body have signed them	SB		Open
94	04.08.2015	Consent workshop to be added to the next agenda in September	SB	On agenda	Closed
95	08.09.2015	Programme Team to identify GP representative for CLH	SB/SP		Open

3. Update on Signatories

- SP updated group that Hounslow GP's have started to sign and CNWL are due to sign.
- Hoping to have HRCH and Hillingdon Council signed for October as going through their respective internal Governance groups
- 150 GP Practises have signed in all

4. Terms of Reference (ToR) - Alistair Robertson

- AR- ToR brought back to the governance group as imperial requested changes to document however they didn't attend governance group in August
- PR- confirmed happy with changes that AR has made to the ToR but would like to highlight that there needs to be another update for when the Care Information Exchange (CIE) is adopted either that or they will need another terms of reference
- SP- we can formally do the update ToR once CIE is adopted as new governance structure will need to be assessed. Still a bit of work to do, between the CIE and this group, this will then provide clarity on new structures.
- AR- We also need to update the reporting lines
- JN- The group needs to consider the patients have to say and how this aligns with the CIE
- SP- need to have some consistency on boards
- JN- legal output will be on the different legal options of consent. Need to make sure that, everything changes so we need to make sure, need to make sure that there are more patients.

Action- Meeting between SG, PR, SP and AT to work through what is required for new governance structure for when CIE is adopted into WSIC ISA.

5. North West London Patient Consent & Choices Workshop October- Dr Aumran Tahir

- AT talked through the proposed agenda with the governance group and requested feedback on structure
- AS- can we get a minimum what is required to be shared, we need to provide assurance
- Group discussion around the background needed before going into the details of the consent models
- AT- setting the scene we will move Alistair and David Stone up the top of the agenda so they can cover the legal and national Information Governance (IG) stance
- SP- the broad outcomes of the discussions we are hoping to have at the event, is that there is a universal understanding in NWL on patient choices and their consent. Some of this will shape some of the CIE outputs, we can use it as a communications.
- PR- CIE, need to get the right people there, we would like to get Mohammed from PKB there to demonstrate

6. Communication Material & Engagement Plans – John Norton & Selin Barnett

- JN- team have been busy going to a lot of different patient groups that are not associated to the WSIC programme, including my Surgeries PPG group to get a non-bias review of the programme material. We hope that this will also result in the final material being easily accessible to all. We welcome some initial feedback.
- SB- we are also aligning the messages to as many of the programmes in NWL as possible so we don't duplicate effort and the same messages are going out to the population, have discussed with Better Care Fund (BCF), CIE, C2C and Care.data
- AS- White against black is hard to read, white background might be better.
- SB- we aim to go around as many patient groups as possible from as a variety of care settings so we can get the best view of how patients perceive the communication material. We have also submitted the material to the Prime Ministers Challenge Fund Fair Processing (PMCF) which is a national workshop being run by NHS England. They are gathering communication material from across the country and asking patients and IG experts to provide comment on them, the aim will be to build a picture of best practise on a national level. We are hoping to have final iterations of the documents by October to support the Early Adopters. I will disseminate final material to all once finished.
- SB- we want to look at adopting the communication strategy once the material is ready.

Action- SB to send final copies of communication material to Governance Group

Action- SB to bring back the communication strategy for formal adoption

PART TWO: Update on WSIC Operational Set Up

7. Whole Systems Data Warehouse – Sonia Patel

- SP- Up and running, various challenges along the way that we have shared with the governance group previously, we've made some good progress with Hillingdon and the other North West London partners, just going through the process of assigning user accounts. We do have McKinsey on board for the next few weeks to make sure the dashboards are fit for purpose.
- SP – continued work going on around dashboard publishing (Intellectual Property), happy to send around a briefing on legal stance

Action- SP to circulate update on dashboard publishing (intellectual property) to Governance Group

8. Risks and issues- Sonia Patel

- SE CSU delivering continues to be the biggest risk to the programme, however intensive support has reduce the risk, there is still a risk while we fit down an SLA arrangements. SE CSU are in special

measures, so their ability to deliver is being diminished. We will continue to keep the governance group updated.

- Intellectual property - see above mitigation

9. Consent to Contact, C2C - Adrian Bull (AB), Jess Henderson (JH), Samia Hasan (SHa) and Barry

First request- C2C Register

- JH- Historically it has been very difficult to recruit patients for clinical trials for the benefit, this has impacted on the development of clinical trials in North West London. The plan is to partner with a successful clinical trial data base in Scotland called Share to help with this design for North West London. We are requesting to hold a list of patients that have opted in to being part of a clinical trial register in the WSIC Data Warehouse.
- AB- at the moment, there is a lot of rig-moral, it will reduce the amount of time and resource needed to do research
- AS-where will the list be held? Who gets to decide who can do the research on the data?
- AB- the Clinical Research Network (CRN) Authority in North West London will decide if a field is viable or not
- JH- the application will only be share a name of agreed person and address if the person has already consented to being on the register
- SP- WSIC have the right analytical licenses, and can safely the authentication the right people to have access, reduces the vulnerability of the wrong information being shared.
- JH- the clinical research network, will be able to use for the ethics which we can share with anyone who would like to see it.
- PR- I'm not 100% who is the Information Asset Owner? Is it imperial healthcare partners or the WSIC? Once we have established that, we can put in the process for who is controlling what? We need sight of a process management centre and a record for all the requests. Does the WSIC Governance Group have oversight of the uses of the data for clinical trials?
- AB- we are not asking for new data, we will compile a list of consented patients, will be known to the share team but not used or goes any further, that whole list they hold will be held.
- SP-need clarity of data hand offs, need to have clarity where the accountability where the roles and responsibility
- AR- I think that we need to figure out who is responsible for who and why they are on the register if a person complains we need to make sure we know who holds possible at who is going on and at one point.
- AT- we will also need site of the communications so we can align work already done from WSIC
- SP- we need to have a phased approach, we need to make sure that this is explicitly consented, difficulty in all of the messages going out
- AR- we would need to change the WSIC ISA to add something to make sure that there is another research purposes and also note the possible implications for the partner providers
- AB- this will be ready in December, we will start to recruit who will be on the register before we could start to use the WSIC data warehouse.
- JH- Earliest we can use the register is July next year
- GT- how it is done in Scotland?
- JH- website and a lot of trained face to face contact with patients. We have also had talks with the CIE about their consent engine?
- SM- where that is recorded and when, it is Unclear? If it's done in the WSIC, if it's a separate people then they will need to define who.
- AB- it will be by the consent to contact team
- SP- are you asking for a supplementary dataset, which will be matched against the original list data?
- DS- we need to figure out who is the data controller for this? We need to make sure that we are lawfully cleared. Sits in the other academic health sites are doing the same thing.
- PR- we need a data flow diagram and the hold offs
- AR- data controllers will be either share or be the data processors of the integrated dataset for Imperial

- BN- ultimately we are doing this for the good of the population to help develop health care in North West London
- AT- asked for the views of the Governance Group
- **Group Decision, can endorse going forward subject to the various noted queries and legal risk review**

Second Request- Feasibility

- AB- we would like to use the Integrated dataset to check that studies can this would feasible or not, this would not be Patient Indefinable Data (PID)
- AS- there are going to be more difficulties using the data for this. Who is making sure that the information shared is appropriate?
- AR- we've written in some stringent controls in the de-identified data, we'd also imposed purposes, only allowed to be used if there is agreement with the Governance Group
- AT- C2C team will need to work this through to come back and define the exact requirements
- SP- I think we can progress, the first part but we'd need to work through the secondary uses, we need to work out roles and responsibilities, what the changes to the ISA and the communications
- **Group Decision, can endorse going forward subject to the legal risk review**

Action- RACIE of the proposed Programme to be shared with the Governance Group

Action- 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.

Action- Legal review of changes of WSIC ISA and associated risks to be brought back to Governance Group

Action- C2C team need to come back to Governance Group with feasibility data request