Discovery Programme Board Meeting
Date: 24th January 2019
2.00pm – 4.00pm

**Venue: FO21 Plaistow Room, 4th Floor, Unex Tower,
Stratford, LONDON E15 1DA**

PRESENT:

Vikrant Abbott (VA)	Newham CCG
Kambiz Boomla (KB)	Clinical Effectiveness Group
Katie Brennan (KBr)	Tower Hamlets CCG
Niall Canavan (NC)	Homerton University Hospital
Carol Dezateux (CDz)	Clinical Epidemiology & Health Data Science, QMUL
Benhilda Dube (BD)	Tower Hamlets CCG
Charles Gutteridge (CG)	Barts Health
Isabel Hodkinson (IH)	Chair, Tower Hamlets Together
Bill Jenks (BJ)	Waltham Forest & East London CCGs
Phil Koczan (PK)	Waltham Forest CCG / UCL Partners
Bhupinder Kohli (BK)	Newham CCG
Luke Readman (LR)	Waltham Forest & East London CCGs
John Robson (JR)	Clinical Effectiveness Group
Andy Thomas (AT)	East London Health & Care Partnership
Martin Wallis (MW)	East London Health & Care Partnership
Dayem Ullah (DU)	Barts Cancer Institute - a Cancer Research UK Centre of Excellence

APOLOGIES:

Niifio Addy (NA)	City & Hackney CCG
Siva Anandaciva (SA)	Patient Representative, Homerton University Hospital
Osman Bhatti (OB)	Tower Hamlets CCG
Ralph Coulbeck (RC)	Barts Health
Sarah Jensen (SJ)	Barts Health
Harry Nyantakyi (HN)	Waltham Forest CCG
David Stables (DS)	Endeavour Health
Paula Turnock (PT)	Endeavour Health
Daniel Woodruffe (DW)	East London Foundation Trust

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1.   INTRODUCTIONS
Introductions took place and apologies were noted as above.

Declaration of Interest

None declared

2.   MINUTES & MATTERS ARISING
Minutes of previous meeting were agreed as an accurate record.

Matters arising from the previous Action Log were raised and addressed:

EMIS delivery of free text (Action 1)
An update on this is requested from PT. LR pushed for this to happen as soon as possible.

HPV Immunisations (Action 2)
This action still to be progressed. LR has asked AT to draft text with CD's input for review by Luke Readman before sending to Kenny Gibson. **Action: AT**

Develop assurance of the data (Action 3)
PT supplied a note (circulated) about the assurance processes which the Data Service apply as standard. The content was noted and agreed by this Discovery Programme Board. **Agreed to close action.**

Whole System Data Project (Action 5)
Now closed from Discovery side. Analysis of the data is in progress. Board requests feedback of information for our reflective learning. Also so that we demonstrate value and benefits to patients e.g. by publishing on the website what has been accomplished using the data.
Action 5 agreed to close.
Open a new action (5a) which is pose questions to IH/the away day for WSDP to glean this type of feedback. Action: CD and IH

Newham Integrated Care System Application (Action 9)
Complete. **Agreed to close.**

N3 Connection with AIMES (Action 10)
PT has provided e-mail confirmation that there is no patient identifiable data with AIMES. LHS hase deleted this data. LR checked on storage data contract termination certificate. PT has requested this – but is not in our hand at the moment. **Close general action.** Leave a line action (10a) open to ensure certificate is received.

Patient views for practices linked to utilities such as APL tool (Action 11)
Ongoing work. Relates to BI harmonisation. **Remain open as ongoing.**

Discovery Information Service to AWS (Action 12)
Completed. **Close action.**

Permissions Management in Trust systems (Action 13)

Now confirmed that for GP data the position is that records with a Type 2 patient opt out will still flow into Discovery, but when retrieved for patient care the opt-out will register and take effect. This is akin to national secondary uses approach.

Leave open for CG to investigate hospital data opt out approach and report back. **Action CG**

Atmolytics (Action 14)

LR has had two meetings with Paul Clifford. On agenda. **Close action**

STP Access to Discovery Data (Action 15)

Application at meeting today. **Close action**

New applications – outer London CCGs data sharing & governance (Action 16)

PK will send KB an e-mail saying what the latest update is on this.

Public involvement (Action 17)

Procured work on this from the Wellcome Trust's UPD programme. KBr requested aligning this work with cross-ELHCP efforts on the same topic, widening scope and applicability.

Close action. New action (17a) CEG share detail of the work procured with KBr to begin this alignment.

AI principles (Action 18)

LR will invite Indra Joshi to meet a group and then will bring back the findings. CD highlighted the role the Office of Life Sciences will play in this.

Share Ian Peters response (Action 19)

The draft materials, including Ian Peters' e-mail with question, are included in papers. Further materials will be shared with Ralph Coulbeck ahead of Jan 31st meeting.

Close action.

3. PROGRESS UPDATES

Annual Report

KB presented the Annual Report, as included in papers. KB commended all for achievements in the past years, and looked forward to the new chapter that is beginning.

The Board endorsed the report, while requesting some additions, removals and enhancements. Agreement was to apply these changes, and publish on Chair's approval.

Action (20) : AT to make the changes, and co-ordinate approval and publication

Changes:
-   KB: Include outer NEL practices where data is flowed now. Work to complete these flows is on-going. DSA issue in BHR is noted.

- KB: There is a question mark that PT knows over Community data. Reference this work to be completed.
- IH: Re RedCap – make clear it's the application process for any purpose, not limited to academia applications
- KBr: Public & Patient involvement: reference that the work will be co-ordinated with the ELHCP approach.
- JR: Include an attractive front-section, some branding etc.
- MW, BJ: Involve comms department in this
- LR: Look & feel to be signed-off by JR
- KBr: Section 1 – explicitly reference connects across the local system and how these have supported the work
- KBr: Section 7 – explicitly reference connects across the local system and how these have played into projects, as discussed at 23.01.19 meeting at Mile End hospital
- IH: Could indicate what CEG's involvement will be in future years
- KBr: Remove out-of-date organisational naming (e.g. TST, ONEL)
- LR: Include what we have learnt – frank statements of the issues we have come across and how problematic e.g. linking has been, showing we are learning from our work
- CD: UPD have standard language of the above type
- KB & CD: Remove or refresh the Q&A section

Technical updates

Barts Health
CD presented on the challenges of interpreting Cerner data, including displaying dataflows and worked example of ambiguous data on a clinical temple. Work to get to a better interpretation is on-going with DS and LHS.
Last week's technical meeting moved us on – we were stuck on validating dates to seek assurance, but have now moved by accepting the completeness of PIEDW data.

Homerton
Homerton are in a different data architecture situation to Barts Health, as do not have a DWH holding Cerner data. NC updated that current approach is to adopt Cerner HIEDW to get a more representative data set than current implementation. Buying this in next financial year.
LR noted this as a learning: that our model may have to change to accommodate having a contract with suppliers to flow their data to Discovery.

Data sharing update

Primary Care: BHR IG update
BJ updated on progress to unblock the finalisation of a DSA in BHR. Dan Weaver CCG chair is now happy. This decisions need to cascade to other involved parties. Some GPs had concerns including liability. Being addressed by direct conversations and CCG policy setting.
BJ will continue to update.

Applications update

Frailty Flag

Number of API hits and resultant number of patients affected was shared (as per papers, p30)

PK referred to a full pack of information and analysis which he can circulate on completion.
LR said next action is an evaluation. PK and LD are planning this in.

The Safety Case Report is in draft form and being reviewed by LD and PK, ahead of sign-off by KB. AT co-ordinating this.

CD said you could use Discovery to look at whether Frailty Flagged patients were admitted.

Atmolytics

There have been two demonstrations in recent weeks with broad range of attendees. KB said one question is whether the PowerBI platform currently being explored as closer working with KBr and Efosa's teams would do the same thing as Atmolytics or whether the product functionality is distinguished enough to be a separate offering. KBr agreed the need for a comparison of the PowerBI and Atmolytics tools.

LR highlighted the need if progressing with Atmolytics to work out how partnering would be structured. A small working group to convene on that topic.

Project register [Decision]

The Board considered three options of how to approach increasing demand for Discovery outputs.

1) Do nothing – continue to engage with new demand as it arises
2) Close to new enquiry – existing (endorsed and in-flight) applications only to come through governance.
3) Managed approach – new applications allowed but are strictly prioritised. Expectations of applicants managed, with lower priority propositions triaged to expect longer turnaround times.

Option 1 was ruled out. The Board considered Option 2 Close to new enquiry. The Board saw risks in that approach including missing out on opportunities to learn from new project subject matter, effect on reputation and system-wide message etc.
Option 3 Managed approach was selected and unanimously agreed. I.e. new applications allowed but strictly prioritised. Expectations of applicants managed, with lower priority propositions triaged to expect longer turnaround times.

Financial updates
The current financial position was discussed. Slight overspend, or with uninvoiced amounts slight underspend.

4.   PROPOSALS & ACCESS REQUESTS

New Applications

- **ELHCP and North East London CCGs: – application approved**
  KBr spoke to the application
  NB that a set of example use cases was listed in this application
  Noted (as per paper) that SLAM data is separately supplied
  Agreed (as per paper) that appropriate permissions from individuals will be sought
  Agreed (as per paper) that a report on the uses would come back to the group annually

  LR noted that this application is a step that builds the capability that the ICS can draw upon.

- **HDR-UK: Natural Language Processing: – application approved**
  CD spoke to the application
  Can go ahead with only Barts data not dependant on Homerton datafeed at this point

- **HDR-UK: Multimorbity: – application approved**
  JR spoke to the application
  LR noted how this standardisation conversations initiates expands our work into regions outside locality of use

- **Pancreatic Cancer Epidemiology: – application approved**
  DU spoke to the application, clarifying difference between this and his first phase application last year. Earlier application was a consented study; this is de-identified

  DU is also applying for Section 251 approval. If successful, that would be a separate approval.
  The Board noted that in this case DU would need to return with a new application before.

  Noted that Barts Health data linkage current situation means linked data will not be immediately available, setting DU's expectations on timing of delivery.
  CG offered to talk to DU about Barts data flow outside of Discovery until linking resolved. If this happens, approval route is different to that agreed today.

  CD added we would like this to be considered a joint application. – i.e. Discovery with CAG or Barts with CAG.

  Next step KB and DU to liaise.

5. STRATEGIC DEVELOPMENT

Harmonising BI platforms in East London
JR presented diagrams proposing how the Discovery data source and existing ELHCP PowerBI platform could be brought together, also involving Public Health as well. Discussion reflects 23rd Jan meeting at Mile End Hospital between Tower Hamlets Strategic Finance team, Efosa and CEG staff.

Intentions supported. Technical steps to be progressed next.

One London LHCRE update
LR updated on the developing picture in the pan-London conversations.

Noted that there is now a stated expectation in the LHCRE deliverables for data layers to be normalised to enable a PHRs and other API-call applications to be supported.

Close to signing contractual agreements.

Barts Health Life Sciences Strategy
CD updated on the part this organisation is taking in the system landscape.

Developing Discovery strategy
Draft documents are shared (in papers) which reflect developing thinking about future strategy – in particular commercial strategy, IP strategy, legal form, return of benefits to data publishers, data protection and security.

Noted that terminology around an 'Insight service' is not current. Discussion about connections between this and themes in One London vision, other connections.

Noted there is further work to be done. A response letter is also being completed.

KBr asked the work and decisions to be transparent. CD updated that a workshop would take place on IP strategy and invited attendees.

The Board noted the enclosed papers and agreed to share these and other materials being prepared with Ralph Coulbeck ahead of the 31st Jan meeting.

6. ACCESS TO DATA FRAMEWORK

RedCap (Research Electronic Data Capture)
CD updated on this tool to be used for Discovery requests for access to data. Online forms and a record or status of application are part of the system.
CD talked through the two-stage application process – process flow diagrams included in the Annual Report as well as full description.

Work continues towards implementation.

UK-SeRP

AT and CD described the stage of discussions on this service, which offers secure hosting to subscribers who cannot assure they have their own. Costs can be routed back through to subscriber in payment model.
LR queried financial costs. CD and AT to supply.

Next step is a pilot. Board asked to endorse and work with CD and AT on how funded. The Board approved a pilot.

AOB

None

Next Meeting: Thursday [ ] <mark>April</mark> 2019
[12.00 – 2.00pm]
[Venue: FO21, 4th Floor, Unex Tower, Stratford]