Public Health England

Agenda

Title of meeting	Data Release Board
Date	20 August 2014
Time	12:00 – 14:00
Venue	LG16, Wellington House, London
Attendees	John Newton (Chair) XXXX XXXX XXXX XXXX (secretariat)
Apologies	Paul Cosford XXXX
Meeting objectives	Receive updates; Agree terms of reference; Discuss SOPs;

1. **Introductions and Apologies**

John Newton welcomed all attendees to the meeting and noted apologies were received from XXXX and XXXX.

2. **Minutes of the previous meeting and actions** (Paper 1)

The minutes of the previous meeting were approved by the Chair.

a. Membership

At the inaugural meeting of the Board, concerns were raised that the membership of the Board could be considered too internal facing by key stakeholders and consequently, the Board discussed expanding membership to ensure appropriate challenge and transparency. In light of these discussions, the Chair of the Audit Committee and Paul Cosford (PHE Caldicott Guardian) were invited to attend the subsequent meetings.

The Chair of the Audit Committee declined his invitation to join the meeting in lieu of additional information regarding the role of Non-Executive Directors and their portfolios of work. XXXX has been asked to respond to a number of questions raised by the Chair of the Audit Committee related to the function of Non-Executive Directors.

Paul Cosford was unable to attend due to prior commitments. The Board recognised there are a number of differences and potential conflicts of interest between the roles of the SIRO and the Caldicott Guardian, alluding to the importance of both governance

functions being represented at Board Meetings. It was agreed that Paul Cosford should be asked to appoint a deputy if unable to attend future meetings.

Action: XXXX to contact Paul Cosford regarding attendance at the next Board meeting and if unavailable, to request that a deputy/associate Caldicott Guardian attends instead.

b) Function

It was agreed that the Board should function as an internally focused body that serves the Accountable Officer, SIRO and public interest by scrutinising the convergence and application of data release standards for explicitly or potentially identifiable data. It was agreed that it should provide an advisory function to equip the SIRO in managing risk associated with the release of data and in their reporting to the Accountable Officer (Duncan Selbie, PHE CEO). This group should have a small formal membership.

Action: XXXX to amend TOR to reflect attendance of the SIRO, Caldicott Guardian and Official Statistician.

It was acknowledged that there is considerable overlap in this remit with the Caldicott Guardian's function to ensure that PHE satisfies the highest practical standards for handling patient information. The Board and CG should actively support work of the ODR to facilitate and enable information sharing and advising on options for lawful and ethical processing of information as required. Questions were raised by the Board regarding who underpins Paul Cosford and how decision making was recorded by these individuals.

Action: JN to request that PC drafts a paper for the Board regarding the function of the Caldicott Guardian (CG) in PHE and background on how PHE is discharging its Caldicott function across different directorates (including record keeping).

Action: PC to provide the Board with a list of all the CGs and assets they support.

c) Secretariat support

XXXX (Research Officer, National Cancer Intelligence Network) will provide secretariat support to the Board in lieu of the recruitment of administrative assistant for the Office for Data Release.

d) Regularity and structure of the meetings

Meeting dates will be established for the rest of the financial year, based on a rolling calendar of three per annum. This has been written into the terms of reference of the Board.

e) Cost recovery and QA metrics

The Board heard a short overview of work to establish a cost-recovery model. XXXX has met with XXXX to discuss how to proceed and XXXX has offered his team to support the development of the model.

Action: XXXX to draft paper regarding the proposed cost recovery model and circulate ahead of the next Board meeting.

f. Data Releases

XXXX noted LSHTM (ODR_2014_34) have received their data following submission of their CAG approval.

3. Approval of the Terms of reference (TOR)

3.1. Data Release Board (Paper 2)

The Board reviewed the Terms of Reference of the Board and approved them subject to minor amendments to reflect the internal governance structure in which the SIRO reports to the Accountable Officer.

It was further agreed that section 4.2 would be removed and the membership of the Board expanded to document that the membership should include the Official Statistician.

In response to conversations regarding the function of the Board, it was felt that the 'Data Release Assurance Board (DRAB)' would reflect the strategic focus and better management of risk.

Action: XXXX to amend the name and terms of reference of the Board to reflect the changes agreed.

Action: JN to extend an invitation to XXXX to join the Board.

3.2. Office for Data Release (Paper 3)

To reflect the conversations of the Board, it was agreed the document would be renamed, 'Functional specification of the Office for Data Release'. Minor amendments were requested to section 3.1 "the ODR will take overall responsibility…" to "ODR is responsible…" and the Board agreed that it was important to clearly define any exemptions or releases outside the scope of the ODR, such as subject access requests or freedom of information requests.

Further amendments were made to sections 4.1 to reflect the roles of the Accountable Officer (AO) and SIRO in managing risk.

Action: XXXX to amend draft terms of reference and to circulate to XXXX for any further thoughts.

4. Update from Office for Data Release

XXXX provided a general overview of the performance of the ODR to date and customer specific updates.

It was noted that current service provision is hindered by lack of substantive posts to take on the expanding portfolio of requests. Through making best use of 'borrowed time' and matrix working the ODR has focussed on the development of appropriate SOPs, the development of the Board, furnishing historic requests and processing applications in accordance to the new controls. It was further explained that XXXX would be meeting with XXXX to discuss repurposing vacant positions within the NCIN to appropriately support the Office for Data Release (ODR).

The Board were asked to consider pump-priming the ODR by asking each directorate to contribute resource to the ODR function, which would enable the ODR to build capacity across the entire agency.

It was recognised that in order to function as an efficient and effective service arm of the CKO, the ODR will require permanent resource. It is hoped that this would be achieved through cost-recovery processes.

Action: XXXX to report to the Board the outcome of discussions with XXXX regarding recruitment within the NCIN and Information Services Teams.

XXXX noted that while the ODR continues to process requests for cancer data, delays in these activities have primarily related to processes being more robust and subsequently, the ODR nurturing a change culture both internally and with external stakeholders.

It was noted that JN shall be meeting with XXXX (Cancer Research UK) to discuss the role of the NCIN and more broadly, issues related to access to data that have caused delays to projects supported by the charity. The Board agreed that communicating the current performance of the ODR should be considered a priority.

Action: XXXX to circulate an overview of the current performance of the ODR.

5. Discussion on the Standard Operating Procedures of the ODR

5.1. SOP0001 Access to potentially identifiable and explicitly identifiable patient-level data for research (Paper 4)

XXXX noted that SOP0001 tries to operationalize how applications for data for the specific purpose of research should be handled. This is process not the criteria. It was noted that feedback has been received from the National Screening Programme.

The Board agreed SOP0001.

5.2. SOP0003 Data Release Register (Paper 5)

In order to maintain public accountability and transparency, the Board agreed that PHE should commit to publishing a registers of the instances where PHE has issued

explicitly or potentially identifiable data. The registers should cover both internal and external releases and in accordance with the SOP0003, list the organisation, the type of data released, the legal basis for release and the specific purpose for release. It was agreed that the Caldicott Guardians should be involved in this process and should have oversight of all data releases. It is not the intention to make this a burdensome process but to be responsive in light of the experience of the HSCIC.

The Board agreed to review SOP0003 to decide whether to include clause 5.1.8 documenting the expiry date of the data reuse agreement and 5.1.9 indication of receipt of data destruction certificate.

The Board agreed that the ODR should provide an indication of the expected publication timescale. It was agreed that this should read, 'At a minimum of an annual register'.

Assuming minor amendments were made to the SOP to reflect these conversations, the Board agreed to ratify SOP0003 and requested that implementation immediately, with the ambition to publish the first register (internally only) by the end of September.

XXXX noted that the development of performance metrics is built into the SOPs. In the spirit of transparency, the Board further discussed public reporting of the ODR's metrics and compliance to these metrics, alongside the register. It was felt that a short briefing aimed at PHE's main critics would be appropriate in the first instance.

Action: The ODR to write a short briefing note explaining the implementation of an external facing register, proposed timelines and methodology for central submissions to the register.

Action: ODR to construct an initial draft of the release register and to circulate to all the Knowledge and Intelligence Teams to request any additional releases of potentially or explicitly identifiable data are captured centrally.

Action: ODR to broker with IAOs capturing all releases across the agency into a single register.

6. National Relationships

6.1. Agreement between NHS BSA and PHE for the monthly supply of pseudonymised record-level electronic prescription data (Paper 6)

XXXX noted that an agreement in now in place with the NHS Business Services Authority to exchange record-level electronic prescription data. The data will be pseudonymised at source and any requirements to identify individuals will need an appropriate legal gateway. The Board agreed that there is substantial value in this linkage, with a number of examples of research uses cited, such as linkage to the congenital abnormalities register to examine prescribing during pregnancy.

6.2. Agreement between Quality Health, NHS England and PHE for the supply of historical and future patient identifiable record-

level National Cancer Patient Experience Survey (NCPES) data (Paper 7)

It was noted that a tripartite agreement for the extraction of the National Cancer Patient Experience Survey has been signed with NHS England and Department of Health. The data will be processed under Regulation 2 of The Health Service (Control of Patient Information) Regulations 2002.

6.3 Access to HES data

The Board received an update regarding access to HES. PHE are in possession of an identifiable extract of HES with limited uses. It was noted that access issues were hindering work programmes that are specific to PHE's public task.

The Board questioned if Regulation 3 of the Health Service (Control of Patient Information) Regulations 2002 could be used to provide an appropriate legal gateway to access HES (inpatient, outpatient and emergency data). It was agreed that further advice should be sought on the use of Regulation 3 for data already in the possession of the agency (commencing with the identifiable cut of HES data).

Action: XXXX to discuss the use of regulation 3 to enable broad access to identifiable HES data with the MRC Ethics, Regulation & Public Involvement Committee (ERPIC).

Action: JN/XXXX to formulate a proposal to the HSCIC to allow PHE to process and use of HES in accordance to PHE's public task and regulation 3.

Development of an ethics oversight group

The Board discussed the need for an appropriate peer review process to ensure fair processing and leadership to the use of regulation 3 as a suitable legal gateway to process data.

This would potentially enable PHE to be self-regulating and with HES data specifically, report retrospectively to the HSCIC on the users and uses of the data within the agency. It was agreed that early engagement and buy in from the HSCIC would be required to provide the necessary level of reassurance. This should be an external facing group, with representation from other data custodians and core stakeholders.

XXXX noted that XXXX is already examining the potential of regulation 3 and drafting an internal definition of 'public health' to cover the broad remit of the agency.

The Board agreed that following this work, PHE should consult external stakeholders on the establishment of an ethics oversight group.

7. Development of a cross-agency policy on disclosure control

The group discussed the value and inherent need to establish or adopt an appropriate anonymisation standard (such as those published by the HSCIC or ONS). It was agreed that the input of XXXX (PHE Chief Statistician) would be integral in developing policy and methodology that reduces the risk of confidential information being obtained from published official statistics, whether as tables or microdata.

It was agreed that the working document created by XXXX should be circulated to XXXX for comments.

Action: XXXX to circulate working document to XXXX for comments on whether PHE should adopt an existing policy or establish new controls.

8. Any other business

Date of the next meeting

Date held – 23rd October, 2-4pm. Board members are asked to confirm their availability to XXXX.