Public Health England

Protecting and improving the nation's health

OFFICIAL

Data Release Assurance Board – June 2017 meeting minutes V1.0

Date	1 June 2017
Time	15:00 – 17:00
Venue	Skipton House, London

Present	XXXXX	National Disease Registration (Chair)
	John Newton	Chief Knowledge Officer & SIRO
	XXXXX	Caldicott Guardian (CG)
	XXXXX	Caldicott Guardian
	XXXXX	National Drug Treatment Monitoring System (NDTMS)
	XXXXX	External to PHE
	XXXXX	Knowledge and Intelligence
	XXXXX	National Chlamydia Screening Programme
	XXXXX	National Screening Programmes
	Professor Kessel	Caldicott Guardian
	XXXXX	Office for Data Release (ODR)
	XXXXX	Office for Data Release
	XXXXX	Office for Data Release
	XXXXX	Office for Data Release (secretariat)
Apologies	XXXXX	National Screening Programmes
	XXXXX	Information Governance and Policy Office (IG Office)

1. Introductions and apologies

17/001 The Chair, deputising on behalf of Professor John Newton, welcomed members of the Board. Apologies were received from the Board.

17/002 The Chair welcomed Professor Anthony Kessel to the membership of the Board following his recent appointment as PHE Caldicott Guardian. It was noted that Professor Paul Cosford has now stood down from this role as PHE Caldicott Guardian.

2. Minutes of the previous meeting and matters arising

17/003 The minutes of the previous meeting held on 4 November 2016 were approved by the Board. All actions of the previous meeting were complete.

17/004	The Board were reminded that in line with the agreed publication schedule and internal approvals procedures, the approved minutes would be made publically available on Gov.UK in due course (https://www.gov.uk/government/publications/data-release-assurance-board-minutes)

3. Health Group Internal Audit Service (HGIAS)

17/005	*a) ODR operational model and extension of function :*
	The Board received a verbal update on actions assigned to the ODR in the HGIAS internal audit of data sharing that remained open.
	Extension of ODR scope to cover all record-level data sharing by PHE Directorates
17/006	The Board discussed the progress in line with timescales recommended by the HGIAS auditors. The ODR explained progress made to integrate non-Health Improvement Directorate assets into the scope of the ODR has been a steady gradual process. Whilst some non-Health Improvement Directorate requests have been taken on, ODR's capacity to extend to be pan –PHE was not possible with current establishment. Resource implications of extending the remit of the ODR to cover the whole PHE was discussed and agreed that this was a Caldicott Guardian responsibility. The Board considered if current cost recovery mechanisms could support this roll out.
17/007	The Board appraised developing a franchised approach for dealing with ODR requests for non-Health Improvement Directorate assets and welcomed the ODR trialling a new data request form which will be migrated into a new digital system. The ODR aim to have this digital applications system in place for the start the 2018/19 financial year.
17/008	Professor Newton noted that a paper was sent to the management committee presenting PHE's information governance priorities. This paper endorsed the need for conformance to the ODR model of assessing requests to disclose data.
17/009	**Action:** Professor Newton to circulate to members the paper presented to management committee and call upon members to highlight priorities.
17/010	Single corporate record maintained of data releases.
	In line with the recommendation for a corporate record of data releases, the ODR shared progress with the publication of the Data Release Register. Following purdah, the register would be updated to cover all ODR releases between 1 January 2017 and 31 March 2017.
	The Board agreed that the extension of the scope of the Data Release Register should be a key priority for the ODR and would enable the ODR to reconcile the resource implications of providing a PHE-wide service. It was agreed that the ODR, in collaboration with

the Caldicott Guardian and IG Office, would appraise options for mandating the inclusion of all instances that explicitly or potentially identifiable data are released for secondary purposes by PHE Directorates into the Register. An action plan to support the implementation of a single approach would be proposed at the next Board meeting.

17/011   **Action:** ODR, CG Function and IG Office to formulate and propose an approach to the corporate roll out of the PHE Data Release Register and present to the Board (by October meeting).

17/012   Professor Kessel questioned progress against the actions assigned to the Caldicott Guardian function within the audit. The Board agreed to review all actions and reflect attainable timescales for completion. Overall responsibility for the audit would also be amended in line with changes to the PHE senior leadership.

17/013   **Action:** NDTMS to work with the Information Governance and Policy Office to re-assess open actions from the HGIAS audit, ownership and assignment of actions to operational teams.

4. Caldicott Guardian function update

17/014   The Board welcomed the newly appointed Caldicott Guardian. Professor Kessel explained that following his appointment he intends to look inwardly at how the Caldicott function is performing, ensure ownership over internal audit actions plans and look for opportunities to strengthen the associate Caldicott Guardian network. It was noted that a call would be scheduled with the Deputy Caldicott Guarian (DCG) and Associate Caldicott Guardians (ACGs) to take stock of key issues and concerns.

17/015   **Action:** Professor Kessel to schedule an open-agenda meeting with the DCGs and ACGs.

17/016   The PHE CG function has significant processes already in place, but there is a need to ensure this data is provided in a more visible product. It was recognised that a functional-driven action plan needs to be made to broaden collective understanding about the role of the CG function, discrete responsibilities and points of escalation, as well as ensuring appropriate management of decisions made across the network. It was noted that the development of this action plan would be a priority for the new Project Manager within the function. This is anticipated to be completed within the next three months.

17/017   **Action:** Caldicott Guardian function to develop functional action plan to support the role out of a robust and visible Caldicott Guardian network. To be completed by 1 September 2017 and circulated to the Board for information.

5. Supporting enhanced subject access requests

17/018   An overview regarding PHE's obligations in responding to Subject

UNCONTROLLED WHEN PRINTED

Access Requests was provided to the Board by the ODR.

17/019   To enhance the way in which the National Cancer Registration and Analysis Service can respond to these requests, and most importantly, support cancer patients to understand how their data is used for research and other secondary purposes; the ODR is working with colleagues in NCRAS to enable SARs to include a patient-level data usage report detailing when data has been released, to whom and for what purpose. This model is to be applied prospectively for every instance that personally identifiable data is released on an individual for a secondary purpose. This report will include full lay summaries of the purpose and links to academic papers published (where relevant). Once implemented within cancer registration, the ODR will look towards integrating into other disease registers within PHE, including the National Congenital and Rare Disease Register.

17/020   To further support this enhancement activity, the Chair stated the importance of an ongoing project to demystify the PHE Data Release Register and present, for each release, a summary in plain English. It was noted that the ODR is currently updating the current summaries and working with a patient advocate group to test the acceptability of the approach taken and ensure that the tone and language is appropriate to a broad audience. It is hoped that the introduction of lay summaries will provide clarity and reassurance to the public about the secondary use of data.

17/021   The Board were informed that applicants will be prospectively mandated to submit a lay summary in accordance with guidance developed by the ODR in collaboration with the patient advocates.

17/022   The chair congratulated the work that has taken place surrounding this and welcomed an update at the next meeting.

6. General update from Office for Data Release

17/023   *a) Year-end report*

The ODR presented a briefing on the delivery of its service function, during the previous financial year (1 April 2016 – 31 March 2017) It was noted that the ODR handled:

- 241 enquiries (representing a 1.2% decrease on the previous fiscal year).
- 148 full applications for data (14% increase on the previous fiscal year
- 37 amendments requests to change the terms of an existing ODR data sharing contact (60% increase on previous fiscal year)
- 88 bespoke data releases for approved applications were made.

17/024   Mean handling time by the ODR for applications where data was

released was 95 working days from the point of enquiry to disclosure of data. This compared to 66 days for releases made during the previous fiscal year. The Board was informed that this interval was unadjusted for delays outside the control of the ODR.

17/025   Concerns were raised by the Board regarding delays ODR were asked to investigate all outliers (mean interval from application submission to release >60 working days). By conducting a root cause analysis of all applications which breached the agreed performance metric. The report should be presented at the next meeting, including, where appropriate, an improvement plan.

17/026   **Action:** The ODR to conduct a root cause analysis of outliers (breaches to 60-day turn around) to ascertain key pinch points and ensure evidence based improvements within the ODR workflow. It was agreed this would be completed by 30/06/17.

17/027   The Board welcomed the introduction of additional performance metrics to future iterations of the annualised summary. In support of this, the ODR noted that the endorsement of the ODR Work Programme would present a clear framework for reporting against broader service deliverables.

b) Work programme 2017-18

17/028   The ODR presented a proposal annual work programme setting out four, non-hierarchical priorities:

1. Delivering a responsive, resilient and transparent data release service.
2. Building capacity and capability by leveraging a digital by default customer journey.
3. Maintaining confidence in PHE's data stewardship role through good governance and risk management.
4. Building the foundations for a PHE-wide service strategy through developing networks and systems.

These priorities, while overlapping at times, have been broken down into respective work plans that have enabled the ODR to identify 'value added' activities to improve the ways in which the ODR manages its (1) customer engagement (2) service delivery and change management, (3) governance and risk management. It was noted that some actions listed have dependencies, including capital funding requirements.

17/029   The ODR welcomed comments from the Board on the content of the proposed work programme.

17/030   The Caldicott Guardian congratulated the ODR on the work programme going forward. Questions were raised about the feasibility of meeting these deliverables and the ODR was challenged about setting SMART objectives. It was explained that the work programme provides a framework approach to assist in the

development of the ODR function. Operational plans, including discrete subtasks and milestones were not presented to the Board.

Members offered suggestions towards how activities, such as measures of customer satisfaction could be grouped. The ODR was asked to review the vision statement presented and suggestions were made that this would be better presented as a mission statement, encompassing the ODR's role, its objectives and its approach to reach those objectives.

Within the work programme, one key priority is the development of a digital system for the ODR approval process to support ODR in building capacity, efficiency and transparency. The Board endorsed the suggested approach to consult with stakeholders on the development of a digital environment.

17/031 **Action:** ODR to review the vision statement.

17/032 The Board welcomed the presentation of Programme-level updates at future meetings to ensure alignment of priorities. The board further requested that a report would be brought to the next meeting to detail programme-level milestones.

17/033 **Action**: ODR to provide a formal update on progress against the work programme priorities, including subtasks and key milestones to the next Board meeting.

17/034 The Caldicott Guardian function broadly endorsed the content of the work programme and agreed it would be beneficial to replicate the approach for the new Caldicott Guardian Office.

c) Patient involvement

17/035 The Board received a verbal update from the ODR regarding the integration of patient and public involvement into the governance of PHE's data release function. It was noted that work was in progress to recruit lay representation to the membership of the Board. The Board were also asked to consider the role of PPI in the assessment of applications.

7. Any other business

17/036 *National Data Guardian Review*

It was noted that in line with purdah conventions, the Government's response to the National Data Guardian (NDG) review of data security and consent (NDG) review is still pending.

17/037 *Next meeting*

The next meeting of the Board is scheduled for 4 October.

17/038 No further updates where made by the Board.

Next meeting of the Data Release Assurance Board:

Actions:

Item #	Action	Action owner
17/009	Professor Newton to circulate to members the paper presented to management committee and call upon members to highlight priorities.	Professor Newton
17/011	ODR, CG Function and IG Office to develop an approach to the corporate roll out of the PHE Data Release Register and present to the Board an action plan to take forward (by October meeting).	Office for Data Release, Caldicott Function and Information Governance Office
17/013	NDTMS to work with the Information Governance and Policy Office to re-assess open actions, ownership and assignment of actions to operational teams.	National Drug Treatment Monitoring System, Information Governance and Policy Office
17/015	Professor Kessel to schedule an open-agenda opportunity to take stock of the current role and performance of the network	Professor Kessel
17/017	Caldicott Guardian function to develop action plan to support the role out of a robust and visible Caldicott Guardian network. To be completed by 1 September 2017 and circulated to the Board for information.	Caldicott Guardian function
17/026	The ODR to conduct a root cause analysis of outliers (breaches to 60 day turn around) to ascertain key pinch points and ensure evidence based improvements within the ODR workflow. It was agreed this would be completed by 30/06/17 and an improvement plan tabled for the next meeting of the Board (October 2017).	Office for Data Release
17/031	ODR to review the vision statement.	Office for Data Release
17/033	ODR to provide a formal update on progress against the work programme priorities, including subtasks and key milestones to the next Board meeting.	Office for Data Release