



OFFICIAL

Data Release Assurance Board – November 2016 meeting minutes V1.0

Date	4 th November 2016	
Time	13:00 – 15:00	
Venue	Skipton House	
Present	XXXX	XXXX (chair)
	John Newton	Chief Knowledge Officer & SIRO
	XXXX	XXXX
	XXXX	XXXX
	XXXX	XXXX
	XXXX	XXXX
	XXXX	XXXX
	XXXX	XXXX
Apologies	XXXX	XXXX
	XXXX	XXXX
	XXXX	XXXX
	XXXX	XXXX

1. Introductions and apologies

16/037 The chair welcomed members of the Board. Apologies were received from the Board.

2. Minutes of the previous meeting

16/038 The minutes of the previous meeting were approved by the Board.

16/039 The Board requested that approved minutes of the Data Release Assurance Board are published on the ODR website following formal approval.

3. Matters arising

16/040 a) ODR website:

The Board were informed that the ODR website was launched in September 2016.

NB: <https://www.gov.uk/government/publications/accessing-public-health-england-data>

16/041 *b) Membership update:*

The XXXX was welcomed to the membership of the Data Release Assurance Board.

16/042 All other outstanding actions are tabled for discussion.

4. National Data Guardian Review of data security, consent and opt-outs

16/043 The Board were presented with an update on the status of the National Data Guardian review and subsequent consultation by the DH on the proposed data security standards, and the proposed consent and opt-outs model for data sharing in the NHS and social care. The Government is expected to publish its response in late November 2016.

16/043 The Board explained that PHE has also been supportive of an overlapping review of informed choice (by Cancer Research UK and Macmillan Cancer Support); the review has sought views from multiple stakeholders about how cancer patients in England could be better informed about the use of their data in cancer registration, and how they can choose whether their data is included. The current information offer has been compared to comparative organisations globally.

16/044 The Board discussed the utility of disease registration data to support direct care, including genetics counselling, local service evaluation/audits and personalised medicine. Concerns were expressed about the impact on direct care and distortion of analyses to support the delivery of cancer services.

16/045 The cancer charities are due to publish this review in November 2016. It was noted that NCRAS recognises the need to reflect upon their recommendations and refine the information offered to cancer patient through engagement and involvement of the PPI community.

5. Health Group Internal Audit Service (HGIAS) – Partridge Style review of data management and releases for PHE – Update

16/046 The Board received a verbal update on the HGIAS internal audit recommendations and reviewed progress against the Management Committee Action Plan. A progress report is to be submitted to the Management Committee by the SIRO.

It was agreed that key to the delivery of these actions was the need for dedicated resource to support the CG function and distributed associate CG network. Resource is necessitated to fully operationalise this function. The update to the Management Committee should emphasise the need for this resource to fulfil the delivery of the action plan.

16/047 The Board supported this request being presented to the

Management Committee and it was acknowledged that due to limitations within CKO headcount, an ESR number must be sourced from a directorate outside of the CKO. If an ESR number can be assigned, NDR will commit funding to support a fixed term role as a cross function of the Office for Data Release or Information Governance and Policy Office, with the Caldicott Function.

6. Caldicott Guardian Function (progress report)

- 16/048 An update was presented to the Board by the Caldicott Guardian Function.
- 16/049 It was noted that a proposals panel is being established to review requests to process data under Regulation 3. It is anticipated these meetings will be monthly. The Board requested the associate CGs from NCRAS and the National Screening Programmes are invited to join these meetings.
- 16/050 The CG function is also exploring training opportunities, such as dedicated webinars. It was noted the NCRAS have an existing eLearning platform that could be further utilised.
- 16/051 The Board noted a change in the risk management matrix to lower the threshold for reporting Caldicott incidents.

7. Patient and public accountability in PHE data release governance and operations

- 16/052 The Board were asked to comment on how the ODR should engage with patient and the public regarding PHE data release functions and integration of this involvement within PHE governance structures.
- 16/053 The ODR explained that patients at the 'UseMyData' workshops have stated that the governance of PHE data release functions should mirror 'patient voice' initiatives within the NHS.
- 16/054 It was agreed that a patient and public involvement advisory function to the Board should be established by the ODR. This should be a small functional group, with clear terms of reference. The chair will be invited to join the Board.

8. General update from Office for Data Release

- 16/055 The ODR presented a summary of ODR performance from 1st April 2016 – 31st September 2016. During this period, 168 projects were handled by the ODR. Of these projects, 61 projects were submitted and reviewed as applications and 40 releases of data were made. Over 90% of these releases were for cancer registration data. In line with the ODR publication schedule, the Data Release Register (available on Gov.UK) has now been updated to reflect all Q2 releases for assets in scope of the ODR.
- 16/056 Questions were raised by members about the ODR's projected throughput to year-end. The Board were informed that there had been a decline in the number of requests from CPRD, as part of the

CPRD-cancer registration linkage. It was further noted that the development and subsequent launch of the NCRAS synthetic, cancer data platform is likely to increase requests from industry.

The ODR is working with the simulacrum development team to ensure there is appropriate supporting guidance in place ahead of the launch of the platform.

16/057 The Board discussed the ODR's plans to capture qualitative feedback to support the delivery of a customer-centric service provision. The ODR will work with the colleagues in the National Cancer Research Institute to deliver a project to capture this information. A new mailing list has already been established to support activity and signpost prospective users of PHE data to new publications on Gov.UK.

16/058 The Board reflected upon the National Infection Service (NIS) approach to handling releases, as approved by their Risk and Governance Group. It was noted that they are actively engaging with the ODR and reporting of NIS data releases will be included on the Data Release Register. Cost recovery is not in place for these requests at this current time.

9. Public accountability

16/059 The Board were informed that the PHE had received a number of FOI requests regarding internal oversight of data releases, staff training and disclosures of data for secondary purposes. The ODR is working with the Public Accountability Team to respond promptly.

10. AOB

16/060 It was noted that NHS Digital has appointed a new chair of the Independent Group Advising on the Release of Data (IGARD).

16/061 The next meeting of the Board is scheduled for 31st January 2017. A call for agenda items and papers will be circulated with the draft minutes.

Post meeting note: The scheduled meeting was postponed due to the availability of members.

Actions:

Item #	Action	Action owner
16/039	The Board requested that approved minutes of the Data Release Assurance Board are published on the ODR website once formally approved.	ODR
16/049	Associate CGs for NCRAS and National Screening Programmes to be invited to proposal panel	CGF

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Approved by:
Effective date
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