



OFFICIAL

Data Release Assurance Board

June 2018 meeting v1.0

Date	6 June 2018	
Time	13:00-15:00	
Venue	Wellington House, London	
Present	John Newton	Director of Health Improvement (Chair)
	XXXXX	Caldicott Guardian Office (deputising)
	XXXXX	National Disease Registration
	XXXXX	Knowledge and Intelligence Division
	XXXXX	Deputy Caldicott Guardian
	XXXXX	National Screening Programmes (deputising)
	XXXXX	Data & Information Governance Policy Office
	XXXXX	Chief Clinical Information Office
	XXXXX	Office for Data Release
	XXXXX	Office for Data Release (secretariat)
	XXXXX	Office for Data Release (secretariat)
Apologies	XXXXX	National Screening Programmes
	Anthony Kessel	Caldicott Guardian
	XXXXX	Deputy Caldicott Guardian
	XXXXX	Information Governance Advisor (External to PHE)
	XXXXX	Deputy Caldicott Guardian

1. Introductions and apologies

- 18/056 The Chair welcomed members of the Board. Apologies were received from:
- National Screening Programmes
 - Anthony Kessel (Caldicott Guardian)
 - Deputy Caldicott Guardian
 - Information Governance Advisor (External to PHE)
 - Deputy Caldicott Guardian

- 18/057 The Board welcomed the deputising representative of the Caldicott Guardian.

2. Minutes of the previous meeting and matters arising

- 18/058 The Board **noted** delays to the publication of minutes of the 4 October 2017.

- 18/059 The minutes were accepted as an accurate record.

- 18/060 The Board reviewed the actions of the last meeting. Where actions were not itemised on the agenda, the matters arising were discussed as follows:

18/006 – ODR to act as single point of access to PHE data for secondary purpose

- 18/061 A verbal update was presented to the Board by the Office for Data Release (ODR). The Board **noted** that from 1 April 2018, the remit of ODR was extended to encompass all requests for the secondary use of PHE assets; where the data requested cannot be rendered suitably anonymised to a standard that would permit publication under an Open Government Licence.

- 18/062 In support of this roll out, the ODR has worked with the National Infection Service (NIS) Senior Management Team and system owners on the delivery of bespoke training to support the integration of new assets and to operationalise these processes across the areas of the Agency. The ODR has further worked closely with the Research, Translation and Innovation Division to support ongoing relationships with PHE sponsored Health Protection Research Units (HPRUs).

- 18/063 It was noted that further work was needed to effectively integrate these new data assets into the ODR processes and that work was in progress to publish a complete list of all datasets that can be requested. The Board **noted** the ODR will need to be explicit surrounding the remit of the requests covered by the team.

- 18/064 The Board discussed PHE policy environment and if changes to

the PHE Information Risk Management Policy were necessary to explicitly state all data access for secondary purposes must be managed through the ODR. It was noted that internal governance pages on PHEnet have been updated to this effect; however the corporate policy is yet to be updated.

- 18/065 **Action:** The Board **agreed** that ODR would produce a decision tree for internal business use, descriptive of when ODR approval must be sought prior to any data disclosure and present this to the Board at the next meeting.

18/008 – National Opt Out

- 18/066 Itemised as Item 4 on this agenda.

18/014 – PHE technical design authority and digital exemplar projects

- 18/067 The Board deferred this action to PHE Digital.

18/021 – Regulation 3 approvals (year to date)

- 18/068 Itemised as Item 5 on this agenda.

18/034 – Implementation of the Wellcome Trust approach to embed Understanding Patient Data (UPD) terminology

- 18/069 The Board received an update on progress made by the ODR on embedding the terminology adopted by the Understanding Patient Data (UPD) Initiative as best practice within ODR products. It was noted that updates the PHE Data Release Register's classifications of identifiability had been prioritised.

- 18/070 The ODR highlighted to the Board that the full adoption of the UPD classification will alter the terminology used in all registers. The Board noted that releases of 'de-personalised' data will now include any data release that meets either (1) ICO Anonymisation Code of Practice, or (2) Anonymisation Standard for Publishing Health and Social Care Data where the data, after review from the PHE Caldicott function, cannot be released under an Open Government Licence due to risks to privacy.

- 18/071 **Action:** The Board **agreed** that the SIRO will present an update to the PHE management committee on changes to the Data Release Register and broader adoption of Understanding Patient Data terms as part of PHE editorial standards.

3. Update on recruitment of Independent Chair

- 18/072 The Board received an update from the Office for Data Release

on the recruitment the Chair of the new independent advisory function to the Data Release Assurance Board. The independent advisory panel will draw together individuals representing the public and patient voice, Faculty of Public Health, and research community to provide impartial advice, oversight and challenge on the strategic and operational approaches PHE deploys to support appropriate data disseminations.

- 18/073 The Board **noted** that the pool of candidates was exceptionally strong and following interviews, conducted with lay representatives, an offer of appointment has been shared. The ODR will now assist the newly appointed Chair to set up the advisory panel.
- 18/074 The Board welcomed the appointment of the independent chair. The Board **agreed** the independent chair should be invited to be an observer of the Data Release Assurance Board.
- 18/075 **Action:** The Board **agreed** the newly appointed Chair should be invited join the Data Release Assurance Board as an ex-officio observer.

4. Update on the implementation of the National Data Guardian opt-out

- 18/075 A verbal update was provided to the Board by the Office for Data Release. The national data opt-out was introduced on the 25 May 2018, allowing individuals to opt-out of their confidential patient information being used for purposes beyond their direct care. This opt out will apply to secondary uses of data, unless specific exemptions are in place.
- 18/076 The Board **noted** PHE's commitment to upholding the national data opt-outs and that ODR would manage this list cleansing process on behalf of PHE to ensure that the national opt out is upheld consistently and in a time-appropriate manner on applicable releases of confidential patient information.
- 18/077 The Board **noted** that the national system, being developed by NHS Digital, for all Health and Social Care data controllers to uphold is still some months away. This new tool is expected to be rolled out under a phased implementation process over the next couple of years to all Health and Social Care data controllers.
- 18/078 As an interim measure, a system is has been developed by NHS Digital to support PHE in upholding the national opt out and is now in beta testing. Once this system is fully tested, PHE will implement opt-outs on all applicable releases of confidential patient information immediately.

- 18/079 The Board **agreed** that messaging about the ODR's role in delivering the directive should be cascaded across the Agency, once the new processing activity has been implemented.
- 18/080 The Board **agreed** the SIRO would present an update to the PHE Management Committee detailing how the Opt Out procedure will be operationalised and associated risk management approaches.

5. Caldicott Guardian Office (progress report)

a) Audit of Caldicott Guardian functional audit – final report

- 18/081 The Board were informed that the final audit report is yet to be disseminated to the Board.
- 18/082 **Action:** The Board **agreed** that an update on the status of the Caldicott Guardian Functional Audit report should be presented at the next meeting.

b) Regulation 3 approvals

- 18/083 The Board **agreed** that a paper summarising these approvals would be shared with the PHE Management Committee by the SIRO.
- 18/084 **Action:** The Board **agreed** that the SIRO will present the list of Regulation 3 approvals to the PHE Management Committee.

6. General update from the Office for Data Release

a) ODR Extension of function

- 18/085 Discussed as per minute reference 18/061

b) Year-to-date report

- 18/086 The Board **noted** the summary of business activity of the ODR for financial year 2017-2018.
- 18/087 The Board noted that there was substantial growth (15%) in the total workload of ODR on the previous financial year.
- 18/088 The ODR presented a survival curve expressing the proportion of applications where approval and access to data took > 60 working days from a valid application being submitted to the ODR (which includes a complete portfolio of evidence to be submitted to the ODR). The Board **agreed** that the information supplied in further reports should be stratified by requestor type and end use to present a more detailed picture.

- 18/089 **Action:** The Board **agreed** that the ODR should provide further descriptive analysis of time to access, expressed by requestor type and end use.
- 18/090 The ODR reported progress to publish all releases made as 'open data' and the scheduled dissemination of these releases via data.gov.uk.
- 18/091 The Board were informed that the National Cancer Registration and Analysis Service plan to publish a list of all extant partnership agreements, which permit data to be accessed within PHE's secure space under specific, time-limited hosting arrangements.

7. Any other business (AOB)

Clinical Practice Research Datalink (CPRD)

- 18/092 The Board **noted** that a new 12 month contract to support the enhancement of the Clinical Practice Research Datalink primary care research database, with data from the National Cancer Registration and Analysis Service, has now commenced. This new agreement extends to breadth of cancer datasets requestors to CPRD can apply for to include patient reported outcome measures.

Update to DRAB terms of reference

- 18/093 The Board **agreed** that the Knowledge and Intelligence Division representative will be invited on an ad hoc basis.

Next meeting

- 18/094 The next meeting of the Board is scheduled for 31 October 2018. A call for agenda items and papers will be circulated with the draft minutes.
- 18/095 No further updates were made by the Board.

Actions summary table:

Item #	Action	Action owner
18/065	The Board agreed that ODR would produce a decision tree for internal business use, descriptive of when ODR approval must be sought prior to any data disclosure and present this to the Board at the next meeting.	Office for Data Release
18/071	The Board agreed that the SIRO will present an update to the PHE management committee on changes to the Data Release Register and broader adoption of Understanding Patient Data terms as part of PHE editorial standards.	Senior Information Risk Owner
18/075	The Board agreed the newly appointed Chair should be invited join the Data Release Assurance Board as an ex-officio observer.	ODR (secretariat)
18/082	The Board agreed that an update on the status of the Caldicott Guardian Functional Audit report should be presented at the next meeting.	Caldicott Guardian Function
18/084	The Board agreed that the SIRO will present the list of Regulation 3 approvals to the PHE Management Committee.	Senior Information Risk Owner
18/089	The Board agreed that the ODR should provide further descriptive analysis of time to access, expressed by requestor type and end use.	Office for Data Release