

OFFICIAL

Data Release Assurance Board - April 2018 meeting minutes v1.0

Date	4 April 2018	
Time	13:00 -15:00	
Venue	Wellington House, London	
Present	John Newton	Director of Health Improvement (Chair)
	Anthony Kessel	Caldicott Guardian
	XXXXX	Information Governance Advisor (External to PHE)
	XXXXX	Deputy Caldicott Guardian
	XXXXX	National Screening Programmes (deputising)
	XXXXX	Data & Information Governance Policy Office
	XXXXX	Chief Clinical Information Office
	XXXXX	Caldicott Guardian Office (deputising)
	XXXXX	Office for Data Release
	XXXXX	Office for Data Release (secretariat)
	XXXXX	Office for Data Release (secretariat)
Apologies	XXXXX	Knowledge and Intelligence Division
	XXXXX	National Screening Programmes
	XXXXX	Deputy Caldicott Guardian
	XXXXX	National Disease Registration

1. Introductions and apologies

18/001 The Chair welcomed members of the Board. Apologies were received from:

- Knowledge and Intelligence Division
- National Screening Programmes
- Deputy Caldicott Guardian
- National Disease Registration

2. Minutes of the previous meeting and matters arising

18/002 The minutes of the previous meeting held on the 4 October 2017 were approved by the Board, subject to corrections of two job titles to reflect changes in personnel.

The Board were reminded that in line with the agreed publication

schedule and internal approvals procedure, the approved minutes would be made publically available on GOV.UK in due course: www.gov.uk/government/publications/data-release-assurance-board-minutes

- 18/003 The Board reviewed the actions of the last meeting. Where actions were not itemised on the agenda, the matters arising were discussed as follows:
- Recruitment of an independent non-executive member*
- 18/004 Itemised as item 3.
- Mandate for all PHE directorates to utilise the Office for Data Release*
- 18/005 The Board received a verbal update on the cross-agency roll out of the Office for Data Release (ODR) application, approval and auditing approaches. Following engagement of the National Infection Service (NIS) senior management team, it was agreed that from April 2018 the ODR would extend their remit to cover all requests to process personally identifiable or depersonalised data for secondary purposes across existing data assets and all NIS data assets. To this effect, the ODR will work with nominated colleagues across the agency to operationalise a hub and spoke network and support the NIS to (1) enhance local capability and understanding about when ODR approvals are necessitated (2) implementation of privacy by design, by default; and (3) the standardisation of data protection impact assessments for all requests for personally identifiable or depersonalised data. Bespoke training with NIS colleagues was already diarised for April 2018 to initiate these processes.
- 18/006 **Action:** The Board agreed that from 1 April 2018, the ODR will act as the single point of access to personally identifiable and de-personalised PHE data for secondary purposes.
- 18/007 The Board noted the benefits of this networked approach, given the resource constraints on the ODR and the imminent need to operationalise the National Data Guardian's (NDG) national opt-out model for data sharing. The Board were reminded that in line with the implementation of General Data Protection Regulation (GDPR), all health and care organisations will be mandated to apply this opt out to secondary uses of data, unless specific exemptions are in place (ie the data is rendered anonymous or an exemption has been authorised by the Secretary of State). PHE is in discussion with its Sponsor about receiving a copy of the national opt-out list, in order to ensure that any opt-outs are upheld prior to data being shared. It was agreed that the management of this process should be centralised and

given the need for consistency for PHE data sharing activities, this should be managed by the ODR.

18/008 **Action:** Should it be agreed PHE receives a copy of the National Opt Out list, the Board agreed ODR will manage the removal of individuals in line with the Government's policy.

18/009 The Board welcomed discussions with the Department Sponsor and NHS Digital on how to operationalise this new process to ensure PHE can appropriately discharge its responsibilities and uphold individual rights.

Paper to PHE Management Committee setting out problems/solutions to extend operational parameters of the ODR

18/010 The Board noted that a paper was presented to the Information Governance Group for the SIRO to subsequently share with the PHE Management Committee. This action was complete.

Dissemination of Caldicott Guardian function audit report

18/011 The Caldicott Guardian noted that the final audit report is yet to be disseminated to the Board as a consequence of delays in completion of the discovery work.

18/012 The Board were provided with a verbal update by the Caldicott Guardian Office on the scope of the functional review and qualitative methodologies used.

18/013 The Chief Clinical Information Officer questioned if the scope of the review extended to digital innovations. It was concluded that this sort of deliberation was outside the functional review and that the review concentrated on the people and processes to support high quality, internal governance systems.

18/014 **Action:** The Board agreed that the Chief Clinical Information Office provides an introduction (in relation to Caldicott's self-assessment surrounding their role and the possible need for their interaction with the Digital team).

18/015 The Caldicott Guardian Office expressed their appreciation to members of the Board for their contributions and support on this project.

Workforce development to improve the training offer to IAOs and System Owners

18/016 The Board received a verbal update from the Information Governance and Policy Office regarding planned revisions to the corporate mandatory training schedule, following interaction with

the People Directorate.

- 18/017 The Board noted that the Regulation 3 framework is not covered in any routine training offered by the UK Council of Caldicott Guardians. Consequently, it was stated that PHE would be the de facto expert in this domain. It was agreed that further exploratory work was required to define and implement a specialist training offer for Regulation 3 activity.

Approvals granted under Regulation 3

- 18/018 The Board received a verbal update on progress made by the Caldicott Guardian to review all processing activity conducted under Regulation 3 of the Health Services (Control of Patient Information Regulations 2002). The Board noted that annual reviews were currently being conducted, and it was expected that a final report on all approvals granted through this review mechanism would be shared with the Data Release Assurance Board in Summer 2018. The Caldicott Guardian noted that additional capacity was recently put in place, in order to support this review cycle.

- 18/019 The Board discussed the terminology used within the regulations relating to processing activities under Regulation 3. Questions were raised around the scope with regard to 'communicable disease', and the relevance of the 'other risk to public health' aspect. The Board discussed on where processing personally identifiable data on public health issues such as tobacco, obesity and substance abuse would sit. The Board agreed that further views were needed and it would be pertinent for the Caldicott Guardian to seek advice from the Department's legal counsel and PHE lay representatives.

Caldicott Guardian function to enhance how colleagues across the Agency engage with the Caldicott Guardian network

- 18/020 The Board was informed that this action remained outstanding; however the Caldicott Guardian function has worked with PHE legal counsel to deliver bespoke training to associate Caldicott Guardians on PHE's authority, under the Carltona Principle, in regards to setting aside the common law duty of confidentiality under Regulation 3.

- 18/021 The Caldicott Guardian noted the creation of the new Caldicott Guardian page on PHEnet.

Operational update on the dissemination of the NCRAS patient leaflet in contact exercises using cancer registration data

- 18/022 The Board was informed that the ODR is working with a number

of applicants requesting to conduct patient contact exercises, where this policy will be enacted. In addition, the ODR is working with the Partnerships and Awareness team to quantify the number of cancer patients in receipt of the NCRAS leaflet, through this specific route.

3. Independent oversight of PHE data sharing - update on recruitment of independent non-executive chair

- 18/023 The Board received a verbal progress update from the ODR regarding the recruitment of an independent non-executive member to Chair the new independent advisory function to the Data Release Assurance Board.
- 18/024 The Board noted PHE had received a number of high quality applications and interviews will be conducted at the end of May 2018.
- 18/025 The Board agreed that on recruitment of the independent chair, the terms of reference of the advisory group will be co-designed with the new chair, as well as broader discussions commenced about the interoperability with the Data Release Assurance Board (DRAB) and other PHE committees, and the recruitment of lay persons to the new advisory function.
- 18/026 The Board drew comparisons to the advisory model utilised by NHS Digital through the Independent Group Advising on the Release of Data (IGARD) and agreed that the DRAB would remain operational as the reporting mechanism to PHE Management Committee.

4. Enhancing transparency – a review of ODR terminology used in public facing documents

- 18/027 The ODR presented a paper summarising external commentary about the use of accessible and transparent language in public facing documentation about data sharing. It was noted that there remains opportunities to refine the manner in which PHE communicates its data sharing activities with the public to aid understanding.
- 18/028 It was explained that the language used by the ODR, specifically in explaining identifiability, had evolved from mirroring the United Kingdom and Ireland Association of Cancer Registries (UKIACR) Data Release Policy; to more recently, adopting components of the language used by the Wellcome Trust's Understanding Patient Data (UPD) initiative.
- 18/029 The Board were asked to consider the formal adoption of Understanding Patient Data (UPD) terminology by the ODR.

- 18/030 The Board broadly endorsed the adoption of UPD terminology throughout all ODR outputs and welcomed engagement with Wellcome Trust about the approaches PHE should take to embed the UPD Initiative (1) as best practice within ODR products, in particular the PHE Data Release Register and (2) more broadly, through the PHE Publications Standard.
- 18/031 The Board discussed co-badging communication outputs with the UPD initiative and the value of extending the use of this best practice across the Agency through integration of this language into the PHE Publications Standard and PHE Gateway clearance process.
- 18/032 **Action:** The Board agreed that the ODR should implement, with the Wellcome Trust, appropriate approaches to embedding the terminology adopted by the UPD Initiative as best practice within ODR products and further agreed, to explore with the Wellcome Trust an endorsement or quality stamp of the PHE Data Release Register once these terms are integrated.
- 18/033 **Action:** The Board agreed the ODR should commence an immediate review of all public and professional facing materials to support implementation of the UPD terminology and as priority, the adoption of these terms in the PHE Data Release Register.
- 18/034 **Action:** The Board agreed that the ODR should engage with PHE Communications Division to explore how strategically and operationally UPD terminology could be implemented across PHE publications.

5. Open Data: making PHE data more accessible, more discoverable, and more usable

- 18/035 The Board received a paper summarising PHE's current position in relation to the public release of PHE data under an Open Government Licence; noting that while PHE has endorsed the principles of Open Data through the PHE Knowledge Strategy, it is yet to adopt an Open Data Policy. The adoption of such a policy was recommended to PHE Management Committee by the Information Fair Trader Scheme (IFTS) auditors and would enable PHE to be more transparent, accountable, participatory and collaborative in the disclosure of open datasets.
- 18/036 The Board discussed progress against the Information Fair Trader Scheme (IFTS) action plan to formally adopt governance arrangements for Open Data; accepting that across the business many data tools, products and reports are routinely disseminated under the limited licensing provisions of the Open Government Licence without a corporate governance approach.

- 18/037 The ODR noted that while every effort is made to apply data minimisation to render bespoke releases anonymous to a standard suitable for public dissemination, the functional and policy remit of the Office for Data Release excludes Open Data requests.
- 18/038 The Board discussed the overlap with PHE Digital Review. The Review is currently identifying digital approaches that could help individuals to take more control of their health, make better use of PHE data; and to enable PHE to be a digital innovator in the health landscape.
- 18/039 The Board endorsed unifying operational practices that support Open Data and considered the business risks of differential operational practices across PHE divisions. It was accepted that the Agency needs to make sure there is balance between risk management; and the need to exploit data to deliver value and improve public health outcomes through knowledge and intelligence.
- 18/040 The ODR noted that the IFTS; which sets and assesses the standards for public sector bodies licensing the re-use of public sector information, was abolished on 1st April 2018. Governance arrangements have been transferred to the Information Commissioner's Office (ICO).

6. Caldicott Guardian Office (progress update)

- 18/041 Caldicott Guardian Office provided an overall update in previous items.

7. Office for Data Release (progress update)

- 18/042 The ODR presented a paper summarising provisional 'year-to-date' service-level activity.
- 18/043 The Board were asked to note the year to date business trends for over the period 1 April 2017 to 28 February 2018. Specifically that within the reporting period, 446 expressions of interest had been receipted, representing moderate growth in the volume throughput of the ODR service. It was projected that the ODR would handle in excess of 500 requests for data by year end.
- 18/044 The ODR further noted that the quantity of successful requests leading to PHE sharing information had also increased. Through the reporting period, 112 data releases were facilitated by the ODR; this represents 131% of the total releases made in 2016-2017.

- 18/045 Of these releases a total of 106 releases were classified as restricted and required contractual controls with time-limited licensing arrangements. A further 6 releases were agreed under an Open Government Licence (OGL).
- 18/046 The Board requested that the ODR explore the presentation of further quantitative measures of service level activity, including using non-parametric methods such as survival curves; and qualitative measures of satisfaction. The challenges of presenting user specific and dataset specific survival curves were discussed. It was further noted that in creating personas and use requirements for the ODR applications portal, the ODR would engage with members to design and define metrics that could be built into the system design to support real time service-level reporting more fluidly.
- 18/047 The Board discussed deploying a survey instrument to provide the ODR with a 360 degree view of current perception of the ODR and enable the ODR to gather in-depth qualitative understanding of stakeholders' needs that could then develop into actionable insights. The ODR explained a discovery exercise was commenced in 2017 to this extent with a view to promote evidence-based culture change; enabling a strategic approach to offer the best customer experience possible and to enable ODR managers to enhance individual and team effectiveness.
- 18/048 The Board noted that given competing pressures on the ODR to resolve a higher number of requests, it accepted this discovery exercise had been paused in order to prioritise GDPR compliance and the direct support of ODR applicants.
- 18/049 **Action:** The Board agreed a final year-end report should be presented at the next meeting of the Board and, where possible, additional analysis on ODR throughput should be presented. Including time from inception to completion as a survival curve.
- 18/050 **Action:** The Board endorsed the development of specific key performance indicators (KPI) by the ODR, which could be used to measure changes in performance over time.
- 18/051 The Board provisionally accepted the year-to-date report and welcomed receiving the final report in Q1 of the new financial year.
- 18/052 It was explained that the ODR continue to work with colleagues within NIS with a view to expand the data assets available through ODR. However, progress is limited due, in the main, the current staffing levels within the core team remaining unchanged.
- 18/053 The ODR provided a verbal update on progress with the NCRAS

Patient Tracker. The Tracking system will enable Subject Access Requests (for NCRAS data) to include a patient-level data usage report detailing when data has been released, to whom and for what purpose. It was noted that the system is now in the beta development stage. A highlight report would be presented at the next meeting of the Board.

8. Any other business (AOB)

Next meeting

- 18/054 The next meeting of the Board is scheduled for 6 June 2018. A call for agenda items and papers will be circulated with the draft minutes.
- 18/055 No further updates were made by the Board.

Actions summary table:

Item #	Action	Action owner
18/006	The Board agreed that from 1 April 2018, the ODR will act as the single point of access to personally identifiable and de-personalised PHE data for secondary purposes.	Office for Data Release
18/008	Should it be agreed PHE receives a copy of the National Opt Out dissent list, the Board agreed ODR will manage the removal of dissenting individuals in line with the Government's policy.	Office for Data Release
18/014	The Board agreed that the Chief Clinical Information Office provides an introduction (in relation to Caldicott's self-assessment surrounding their role and the possible need for their interaction with the Digital team).	Chief Clinical Information Office and Caldicott Guardian Office
18/032	The Board agreed that the ODR should implement, with the Wellcome Trust, appropriate approaches to embedding the terminology adopted by the UPD Initiative as best practice within ODR products and further agreed, to explore with the Wellcome Trust an endorsement or quality stamp of the PHE Data Release Register once these terms are integrated.	Office for Data Release
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