



OFFICIAL

Data Release Assurance Board February 2019 Meeting

Date 19 February 2019

Time 10:00-12:00

Venue Wellington House, London

Present

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|------------------------------------|---|
| Professor John Newton XXXXX | Director of Health Improvement (Chair) |
| XXXXX | National Director for Disease Registration & Cancer Analysis |
| XXXXX | Chief Clinical Information Officer |
| XXXXX | Deputy Caldicott Guardian (communicable disease) |
| XXXXX | National Screening Data and Information Lead (deputising) |
| XXXXX | Lead, Office for Data Release |
| Professor David Forman XXXXX | Chair, Independent Advisory Panel on Data Release |
| XXXXX | Associate Caldicott Guardian, PHE Screening |
| XXXXX | Office for Data Release (secretariat) |
| XXXXX | Office for Data Release (secretariat) |

Apologies

| | |
|-----------------------------|---|
| XXXXX | Director of Programmes for the UK National Screening Committee |
| XXXXX | Data & Information Policy and Partnerships Lead |
| XXXXX | Information Governance Advisor (external to PHE) |
| Professor Anthony Kessel | Caldicott Guardian |

1. Introductions and apologies

19/001

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

- Director of Programmes for the UK National Screening Committee
- Data & Information Policy and Partnerships Lead
- Information Governance Advisor (External to PHE)
- Professor Anthony Kessel

19/002 The Board noted a number of personnel changes were underway within the PHE Caldicott Guardian network, namely:

- Professor Kessel will be leaving his role as PHE Caldicott Guardian
- The incumbent Deputy Caldicott Guardian (communicable disease) will step down from membership of the Data Release Assurance Board
- A vacancy for the Deputy Caldicott Guardian (non-communicable disease)

19/003 The Board requested that the impact of these changes and the resourcing of the Caldicott Guardian Office be discussed under Item 4 to better understand what succession planning is in place, and how business continuity will be maintained through the transition between the departing and incumbent Caldicott Guardians.

2. Minutes from the previous meeting and matters arising

19/004 The Board discussed the draft minutes of the previous meeting (October 2018) and agreed the following revisions:

i) 18/102 Update to the McNeil Review

19/005 The Board noted a correction made by the Chief Clinical Information Officer that: the title in item 3 should be revised from 'McNeil Tailored Review' to the 'McNeil Review'.

ii) 18/103 – Assignment of primary data collections

19/006 The Board agreed the text should be revised to 'The Chief Clinical Information Officer summarised the number of data collection in each tranche'.

19/007 The Board reviewed the actions for the last meeting. Where actions were not itemised in the agenda, the matters arising were discussed as follows:

18/104 – Assignment of primary data collections

19/008 The Chair encouraged the Board to provide feedback to the Chief Clinical Information Officer to support business case development and thanked Members for their contributions made thus far.

18/105 – Assignment of primary data collections

19/009 The Chief Clinical Information Officer noted that the recommendation of the Board had been conferred to the Joint Working Group programme team.

18/112 – Implementation of the Independent Advisory Group

19/010 Itemised as item 3 on this agenda.

18/120 – Caldicott Guardian Office resourcing

19/011 Itemised as item 4 on this agenda.

18/126 – ODR exception report

19/012 Itemised as item 5 on this agenda.

18/132 – Declassification of Date of Death by NHS Digital

19/013 The Board noted that NHS Digital has re-classified Date of Death from a 'direct identifier' to an 'indirect identifier'. To this regard, Date of Death is no longer treated by NHS Digital as identifiable unless it is accompanied by other data that would enable identification to be reasonably likely by any likely means in the hands of the data recipient.

19/014 The Board noted the ODR has mirrored this change within their own approval due diligence and will communicate this change to the public, via the Data Release Register.

19/015 In response to this call for advice and broader discussions about this change, the Board asked the Chair to contact NHS Digital and the Departmental sponsor to clarify the scope of this change, including:

- impact on upholding the National Opt Out consistently between all Arm's Length Bodies

- what communications had been provided to the public to support open and fair dialogue regarding this change

19/016 The Board re-iterated their concerns as discussed in October 2018 about the visibility of a consultation on this change and lack of available information to the public that explains when and why this change was implemented. It was noted by the Board that the Chair is liaising with NHS Digital Executive Director for Data, Insights and Statistics.

19/017 **Action:** The Chair to provide an update on discussions with NHS Digital and the Departmental sponsor on the impact of declassification of date of death at the next meeting on:

- impact on upholding the National Opt Out consistently between all Arm's Length Bodies
- what communications had been provided to the public to support open and fair dialogue.

18/134 – Advice to applicants on no longer requiring an exemption to common law to process date of death

19/018 The ODR is unclear what advice should be given to prospective and current applicants who have an extant exemption under Regulation 5 to process Date of Death alone (without other direct identifiers) with regard to the maintenance of this exemption to common law.

19/019 The ODR noted it is working with the Health Research Authority (HRA) to make sure that any advice provided to applicants is consistent with their expectations and uniform across all arm's length bodies handling health data.

19/020 **Action:** The ODR to provide an update on discussions with the HRA at the next meeting.

19/021 The ODR asked for advice from the Board on updating the Data Release Register to reflect that specific historic releases will no longer be considered personally identifiable.

19/022 The Board deferred their policy decision until discussions were finalised with NHS Digital and the Departmental sponsor.

18/137 – Hospital Episode Statistics Analysis Guide with NHS Digital

19/023 Action delegated by the Chair to the Information Governance and Policy Office (IG Office). The Board noted discussions are ongoing.

18/138 - PHE Policy for handling small numbers when releasing aggregate statistical data policy owner

- 19/024 The Chief Clinical Information Officer noted that this action was assigned in his absence and asked for further clarity on the scope of the discussion. Action deferred till the next meeting.
- 19/025 **Action:** The Secretariat to provide further clarity on the scope of this discussion to the Chief Clinical Information Officer.
- 19/026 The Board were reminded that in line with the agreed publication schedule and internal approvals procedure, the approved minutes would be made publicly available on GOV.UK in due course: <https://www.gov.uk/government/publications/data-release-assurance-board-minutes> .

Independent Advisory Panel on Data Release (IAPDR) progress report

- 19/027 The ODR presented a paper detailing progress with recruitment of members to the IAPDR.
- 19/028 The Board noted that recruitment to the Panel commenced in January 2019 through two mechanisms:
- 1) The utilisation of open recruitment for three Advisory Panel Members (Patient and Public Voice) through an online media outlet and NHS jobs.
 - 2) The appointment of Advisory Panel Members (Professional communities) who will be nominated by the community of interest following a letter to senior leaders from the PHE Chief Executive inviting that they formally nominate a representative.
- 19/029 The Board noted that several patient liaison groups had supported the dissemination of the advert of Advisory Panel members (Patient and Public Voice) and by close of the advert, the IAPDR Chair had received over 20 applications for the three posts. Professor Forman acknowledge the positive response, calibre of the submissions and noted and 6-8 candidates will be interviewed on 26 February 2019. It was further confirmed that candidates for the three Patient and Public Voice members will be informed of the outcome of the selection panel on 01 March 2019.
- 19/030 The ODR provided an overview of planning to support the induction and ongoing learning of IAPDR Members; noting that all Members are required to attend an induction day on 18 March 2019. The IAPDR Chair has extended invitations to colleagues in

PHE who support the governance of data collections and to external speakers, who interact with the ODR as customers and represent the views of the public.

- 19/031 The IAPDR Chair advised the Board that the first official meeting of the IAPDR will take place on 01 April 2019 and this meeting will concentrate on the governance and administration of the IAPDR; including ratification of the terms of references and agreement on ways of working.
- 19/032 The IAPDR Chair asked the Board to consider how they would like the two groups to work effectively to create a two-way feedback mechanism that best supports PHE to effectively deliver its data release functions and the mandate provided to the Panel by the PHE Chief Executive.
- 19/033 The Board discussed the sequencing of meetings and how advice will be sought from the IAPDR. The Board agreed that IAPDR meetings should be 6-8 weeks prior to the DRAB and the Board should have a standing item to reflect on (1) new requests for advice from IADPR and (2) responses from IAPDR.
- 19/034 The Board recommended to Professor Forman that once recruited, IAPDR Advisory Panel members should be asked to consider how they want to liaise with the DRAB and agreed that the agenda of subsequent meetings should be updated to reflect this two-way feedback loop.
- 19/035 The Chair extended his thanks to the IAPDR Chair and secretariat for their support with formally constituting the IAPDR and requested that a summary paper is made available for the PHE Management Committee expressing PHE's current progress with the Panel. The Board discussed opportunities for updating PHE staff and external stakeholders about the role of the Panel and requested an updated on the communication strategy being deployed.
- 19/036 **Action:** The Board agreed that the ODR is to produce a summary paper explaining the remit of the IAPDR to the Management Committee.
- 19/037 The ODR noted that a blog was authored on behalf of Professor John Newton to announce recruitment of the function, remit and membership of the IAPDR in November 2018; however due to resourcing issues within the Communications Division, this remains unpublished. The ODR expressed their frustration with the lag in publicly announcing Professor Forman's recruitment and how IAPDR will be formed and welcomed support from the Board on how best to engage the Communications Division to

support the timely production and publication of future materials about IAPDR or the Board.

- 19/038 The Board noted that planning was underway to support the IAPDR to publish the IAPDR terms of reference and biographies of the Members, once agreed. These will be placed on gov.uk.
- 19/039 The Board reflected the importance of internal communications about the remit of the ODR. ODR noted that updates are planned for the PHE intranet, including a digitised decision tree that communicates to PHE staff when ODR approval must be sought. The decision tree will also highlight to PHE staff other operational teams with responsibility for handling data requests, such as, Freedom of Information Requests or Subject Access Requests, which will be outside the remit of the ODR.
- 19/040 The Board reflected on the difficulties the ODR has faced with publishing information about IAPDR and were advised to liaise directly with the lead of PHE communications team.
- 19/041 **Action:** The ODR to report progress on internal and external facing communications at the next meeting.
- 19/042 The Chair expressed their gratitude to the IAPDR Chair for the progress with constituting the IAPDR.

General update from the Caldicott Guardian Office

- 19/043 The Deputy Caldicott Guardian (communicable disease) provided a verbal update to the Board. They noted that Professor Anthony Kessel (the incumbent PHE Caldicott Guardian) will be stepping down from his position in March 2019. The Board expressed their appreciation for Professor Kessel's contribution to the development of the Caldicott Guardian Office, it's associated network and his participation in the DRAB.
- 19/044 The Board noted that the new PHE Caldicott Guardian will be the incoming Deputy Medical Director. The Board further noted that the successor to the outgoing Deputy Caldicott Guardian (communicable disease) has been appointed and would be invited to subsequent meetings of the DRAB.
- 19/045 The Board were asked for their support in identifying a second Deputy Caldicott Guardian who will be responsible for the oversight of non-communicable disease data collections and associate Caldicott Guardians within this area.
- 19/046 The Board requested an update on progress made with the identification of resource to sustain the Caldicott Guardian Office administrative support and in extending the number of WTE

available to support the PHE Caldicott Guardian. Feedback was provided by the Deputy Caldicott Guardian (communicable disease data collections). The Deputy Caldicott Guardian explained that support was being sought for additional funding from the Investment and Approvals Subgroup (IASG).

19/047 The Board expressed the importance of this internal structure to PHE's data and risk management approaches.

19/048 The Board recommended that the Caldicott Guardian liaise with the PHE Resourcing and Prioritisation Group (RPG) to support with funding for new posts.

General update from the Office for Data Release

19/049 The ODR presented a paper summarising activity during the first 10 months of the 2018-2019 financial year.

19/050 The Board noted the mean time to release over the reporting period was 69 days (median 59 working days), which exceeds the target of 60 working days elapsing from application to release. The ODR noted that, this interval is unadjusted for stop-starts outside of ODR's control (such as contract negotiation or the provision of cohort master files support data linkage to PHE assets for a defined population) which increase the lead time to the provision of data.

19/051 The ODR explained that thirteen requests have been facilitated through the Clinical Practice Research Datalink (CPRD) linkage scheme, allowing cancer registration to be made available to CPRD clients. The Board were also informed that the ODR has a 10-day turn around Service Level Agreement with CPRD.

19/052 The Board discussed the approach taken by the ODR to cost recovery and how this compares to other data custodians in terms of affordability and pressures of the public purse. The ODR noted that for data releases subject to charging during this period, the mean amount cost recovery under the ODR Products and Services Cost Recovery Policy was £2646.00 per chargeable request. The Board noted that this figure was significantly lower than other data providers.

19/053 The Board welcomed the addition of exception reporting to the year to date report and questioned if more granular analysis was available on why delays occurred.

19/054 The Board agreed end of year reporting by the ODR should quantify delays in a meaningful way so that they can be tracked and opportunities to remedy these delays in future requests acted on by the Board and respective Information Asset Owners.

The Board further agreed that a sub-set of these applications should be reviewed at the next meeting of the Board (top quartile).

19/055 **Action:** The Board agreed that the ODR is to produce an end of year report for the next Board meeting. This report should represent a detailed root cause analysis of significant breaches (top quartile) to the 60 working days target.

19/056 The ODR noted that the Data Release Register was being quality assured and committed to updating and publishing the PHE Data release register by the end of February 2019.

19/057 **Action:** The ODR to publish an update to the PHE Data Release Register to include releases up until 31 December 2018 by end of February 2019.

Strategic relationships

19/058 The ODR noted discussions on the data collections to be included under the Clinical Practice Research Datalink (CPRD) linkage scheme was underway and a revised contract was with CPRD.

19/059 The ODR explained that CPRD has expressed their interest in expanding the data collections available through this scheme to include screening data and communicable disease data. To this regard, ODR had adapted the conditions within the contract to enable new data collections to be integrated as approved data collections, where CPRD possess an appropriate legal basis, without the need to re-issue or execute variations on the standard contractual framework.

19/060 The Board welcomed the emerging relationship with Health Data Research UK (HDRUK) as part of a research alliance and heard from the Chair about planned collaborations with NHS Digital, including ongoing discussions about technological solutions such as virtual research environments. The Board relayed their enthusiasm for cross-ALB partnerships.

Proposed Key Performance Indicators (KPIs) for Office for Data Release for 2019/2020 financial year

19/061 ODR informed the Board of progress with the development of an electronic application system. The Board were invited to contribute to the development of this system and asked to identify key targets or performance measures they would like to be included in standard reports or available in real-time dashboards.

19/062 The Board discussed the merits of quantitative data on the handling of ODR requests and expressed the value in qualitative assessment of the perception of the service ODR provides post approval. The Board asked the IAPDR to consider the value of distributing stakeholder satisfaction surveys of this nature.

19/063 **Action:** Advice to be sought from IAPDR on the development of a stakeholder satisfaction survey

National Opt Out Programme – launch of training proposition from ODR

19/064 The ODR explained it had designed and tested a new training proposition with NCRAS analysts to explain how PHE is implementing the National Opt Out Programme for PHE. Work is ongoing to adapt this training offer based on feedback prior to rollout across PHE.

19/065 The Board further noted that the requirement to uphold the National Opt Out has been included in the content of an e-learning resource that is currently in beta testing phase.

Any other business (AOB)

Egress Switch

19/066 The Board noted that planning was underway by the ODR to adopt 'Egress Switch', to support the transfer of data between PHE and third parties. It was noted that with the roll out of new laptops across PHE, this new tool would soon be available to all staff.

Setting up NHS X

19/067 The Chair of the meeting provided a brief verbal update on the new digital unit in government. It was noted that no resourced is expected to be extracted from PHE.

Strategic prioritisation

19/068 The Chief Clinical Information Officer is working on the overarching priorities on data infrastructure. This is project is ongoing.

Next meeting of the Data Release Assurance Board

19/069 The next meeting of the Board is scheduled for 08 May 2019. A call for agenda items and papers will be circulated with the draft minutes.

19/070

No further updates were made to the Board.

Actions summary table

| Item # | Action | Action owner |
|---------------|---|---------------------------------------|
| 19/017 | The Chair to provide an update on discussions with NHS Digital and the Departmental sponsor on the impact of declassification of date of death at the next meeting. | Professor John Newton |
| 19/020 | The ODR to provide an update on discussions with the HRA at the next meeting. | The Office for Data Release |
| 19/025 | The Secretariat to provide further clarity on the scope of this discussion to the Chief Clinical Information Officer. | Office for Data Release (Secretariat) |
| 19/036 | The Board agreed that the ODR is to produce a summary paper explaining the remit of the IAPDR to the Management Committee. | Office for Data Release |
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