



OFFICIAL

Data Release Assurance Board – October
2018 meeting minutes

Date 31 October 2018
Time 10:00-12:00
Venue Wellington House, London
Present

| | |
|-------------------------|--|
| John Newton | Director of Health Improvement (Chair) |
| Anthony Kessel XXXXX | Caldicott Guardian Information Governance Advisor (External to PHE) |
| XXXXX XXXXX | Deputy Caldicott Guardian National Screening Programmes (deputising) |
| XXXXX | Information Governance & Policy Office |
| XXXXX | Chief Clinical Information Officer |
| Professor David Forman | Chair, Independent Advisory Panel on Data Release (IAPDR) |
| XXXXX XXXXX | Office for Data Release National Screening Programmes |
| XXXXX | National Screening Programmes |
| XXXXX XXXXX | National Disease Registration Office for Data Release (secretariat) |
| XXXXX | Office for Data Release (secretariat) |
| Apologies | |
| XXXXX | National Screening Programmes |
| XXXXX | Caldicott Guardian Function |

1. Introduction and apologies

18/096 The Board welcomed members of the Board. Apologies were received from:

- National Screening Programmes
- Caldicott Guardian Function

18/097 The Board welcomed the newly appointed Chair of the Independent Advisory Panel on Data Release (IAPDR), Professor David Forman and noted he would participate in the Board meetings as an ex-officio member.

18/098 Professor Forman was introduced to the Board, a summary of his Biography can be found below.

Professor is Visiting Professor in the School of Medicine, University of Leeds. Prior to retirement from full-time work in 2016, he was Head of the Section of Cancer Information at the International Agency for Research on Cancer (IARC) based in Lyon, France.

2. Minutes from the previous meeting and matters arising

18/099 The minutes were accepted as an accurate record.

18/100 The Board were reminded that in line with 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>

18/101 The Board reviewed the actions of the last meeting. Where actions were not itemised on the agenda, the matters arising were discussed as follows:

18/065 – Office for Data Release (ODR) to produce a decision tree for internal business use, descriptive of when ODR approval must be sought prior to any data disclosure

18/102 Action incomplete and deferred to the next meeting.

3. Update to McNeil Review

18/103 The Chief Clinical Information Officer presented a verbal update on progress made against the McNeil Review implementation plan. It was reported that the Joint Working Group had agreed ways of working, and completed the assignment of PHE's primary data collections into one of 4 tranches:

- data collections which could potentially be transferred in short order (around 12 to 18 months)
- data collections with more complex requirements which should be considered in the medium term (18 months to 3 years)
- the National Cancer Registry and the National Congenital Anomaly and Rare Diseases Registry which should be considered over the longer term (3 to 5 years)
- data collections that should remain with PHE, these will include:
 - a) those that support the real-time or near real-time provision of patient or population facing public health

- services as part of PHE's core functions in areas such as health protection case incident management;
- b) data collections performed on the basis of contractual activities on behalf of other organisations (e.g. laboratory results); and
- c) non-mechanistic/ non-automated data collections requiring significant public health expertise in identifying and entering the required data.

18/104 The Chief Clinical Information Officer summarised the number of data collection in each tranche.

18/105 **Action:** The Board agreed to provide feedback through to the Joint Working Group on the variable benefits and needs of users to support business case development. Feedback to be provided directly to the Chief Clinical Information Officer.

18/106 **Action:** The Board agreed that the Joint Working Group should include within the scope of each business case a cost-benefit analysis, which identifies the strategic benefits of transferring data controllership of specific data collections to NHS Digital.

4. Implementation of the Independent Advisory Panel on Data Release (IAPDR)

18/107 The ODR and IAPDR Chair presented a summary paper for discussion; outlining proposed terms of reference (ToR), membership and the recruitment strategy for the Independent Advisory Panel on Data Release (IAPDR). The Board was asked to:

- 18/108
- comment on the draft terms of reference of the Independent Advisory Panel
 - comment on the representativeness of the proposed membership and whether all appropriate communities of interest have been identified for inclusion in the membership;
 - agree the draft terms of reference of the Independent Advisory Panel, and
 - agree the recruitment strategy of the Chair and the Panel secretariat.

18/109 The Board welcomed that the Independent Advisory Panel on Data Release will provide the PHE Data Release Assurance Board with authoritative and independent advice and make recommendations, on:

- the decisions and priorities of PHE in support of the sharing of PHE data for secondary purposes;
- the effectiveness and integrity of existing PHE policies and procedures to support appropriate, timely data sharing for secondary purposes
- the extent to which PHE organisational culture, policies, and fair and due process procedures with regards to data sharing are customer-centric and focused on improving operational delivery for service users.

- the interactions, alignments and responsibilities of the ODR and other relevant services, including third-party agencies (such as NHS Digital)
- the adequacy of current independent oversight, advocacy and the process mechanisms for complaints or appeals made to the ODR
- the public and professional impact of PHE as a custodian of data;
- delivering transparent and effective public communication related to PHE data sharing for secondary purposes; and
- any other issues that the Independent Advisory Panel on Data Release believe are necessary to be considered by the Data Release Assurance Board in support of legitimate and lawful sharing of PHE data for secondary purposes.

- 18/110 The Board noted that the Panel will not perform an application review function akin to Independent Group Advising on the Release of Data (IGARD) and that the Data Release Assurance Board will remain the reporting mechanism to PHE Management Committee.
- 18/111 The Board agreed the terms of reference and recruitment strategy proffered by the IAPDR Chair and ODR. Discussion was held about opportunities to broaden the reach of the membership.
- 18/112 The Board agreed that the Chair will have the autonomy to agree the appropriateness of membership and in support of initial implementation, endorsed the proposed membership of 11 members; however, agreed that membership should continue to be reviewed by the Chair to reflect the requirements of the Panel in delivering their remit. It was noted recruitment would therefore commence to identify:
- 3 consumer representatives (patient and public voice)
 - representative of UK Faculty for Public Health
 - representative of the Royal Colleges
 - representative of the National Cancer Research Institute
 - representative from industry/private sector
 - 2 representatives of the academic community, nominated by HDR-UK and NIHR
 - one information governance advisor, potentially a representative drawn from the Office of the National Data Guardian
- 18/113 **Action:** ODR to provide secretariat support to the IAPDR Chair to commence recruitment to the Independent Advisory Panel on Data Release.
- 18/114 The Board discussed the short and medium term priorities of the IAPDR.
- 18/115 The IAPDR Chair noted the following suggestions from members:
- governance of open data releases
 - availability of PHE resources for secondary purposes – missed opportunities
 - acceptability and fitness of current processes for sharing data, including areas of vulnerability or risk
 - how do we improve communication mechanisms to relay the value of and benefits that can be realised through PHE data collections
 - emergence of new technology, such as AI

- who else is doing this really well that we could learn from

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

- 18/116 The ODR presented a verbal update on implementation of the national data guardian opt-out. It was noted that using a new national system provided by NHS Digital, PHE is applying the national data opt out to releases of personal confidential data. The attrition rate per release has been between approximately 2-3%. The Board were informed that NHS Digital continues to publish national dissent rates and these are comparable to the range identified by ODR when using the system.
- 18/117 The Board noted that the ODR was in the process of delivering training to the national disease registration service, with the view to extending the availability of training on the implementation of the opt out process within PHE, in early 2019. Supporting documentation will be made available on PHEnet.
- 18/118 The Board noted that commitments had been made by Government to enable the population to express their preferences using a digital app, and noted further updates on progress by NHS Digital to develop and launch this tool would be provided to the Board once available.

6. General update from Caldicott Guardian Office (Chaired by JN)

- 18/119 The Caldicott Guardian Office presented the findings of the Review of the Caldicott Guardian function. The review set out to explore the effectiveness of arrangements for the delivery and governance of the Caldicott function, and to make recommendation on how the function could be further strengthened. It was noted this internal review gathered evidence from synthesis of pre-existing documentation(s), benchmarking against other organisations, and stakeholder interviews.
- 18/120 The Board welcomed the review and reflected on the importance of the Caldicott Guardian function in safeguarding high standards of governance as part of the Agency's broader risk management strategy. The Board questioned if sufficient resources are in place to fulfil the recommendations of the review and following discussion, agreed the approximate costs outlined in recommendation 6 should be revised to strengthen the function's resilience and enable business continuity. The Board advise the Caldicott Guardian Office revisit the staffing requirements and associated overheads. The Board further recommended that the inclusion of both units and associated costs, as well as benchmarking against comparative functions within NHS Digital or an NHS Trust.
- 18/121 **Action:** The Board recommended that the Caldicott Guardian should revisit the staffing costs outlined in the paper to ensure resilience to deliver the 6 recommendations outlined in the Review.
- 18/122 The Caldicott Guardian expressed their appreciation for the Board's inputs into the conduct of the review and noted that the review would subsequently be shared with PHE Management Committee for corporate endorsement.

7a. General update from the Office for Data Release (ODR)

- 18/123 The ODR presented a paper detailing midyear view of the business activity of the ODR for financial year 2018/2019.
- 18/124 The Board noted that during the period the total number of new enquires and applications combined was 193 requests. This represents a decline in the volume of new enquiries and new requests to the ODR comparatively to the same period in 2017/2018. The Board questioned the ODR about why the cause of this decline and the ODR noted that there were no clear trends emerging, however, anecdotally applicants were being more strategic in their applications and through utilising pre-application advice the ODR was less likely to receive requests for amendments to data specifications.
- 18/125 The Board welcomed that 74 data releases had been approved and released by the ODR during the reporting period. The Board questioned the lead time from a complete application to data dissemination and whether there were any specific challenges that the team encountered in meeting the 60 business day target. The ODR noted that the mean time to release over the reporting period was 62 business days and there remain some challenges that hinder the ability to meet this target, such as:
- requests being increasingly complex reflecting the availability of new data collections and data linkages
 - applicants often requiring educating on GDPR or research governance requirements
 - ODR not having direct access to, or knowledge of, each data collection, therefore is reliant on the capacity and capability of colleagues across the agency.
- 18/126 The Board noted the challenges faced by ODR in delivery of its function and agreed that it would be beneficial to receive an exception report detailing instances where data was not disseminated within 60 working days of a complete application. The Board agreed that a classification system to explain these delays should be proffered to the Board.
- 18/127 **Action:** The ODR to produce an exception report detailing instances where data was not disseminated within 60 working days of a complete application and to present this report to the Board at the next Data Release Assurance Board meeting.
- 18/128 The Board welcomed the inclusion of a survival curve in the paper and feedback was provided to the ODR. The Board agreed that the ODR would present at the next Data Release Assurance Board meeting the updated survival curve to reflect the feedback given including types of users and end use of the data.

7b. PHE Data Release Register

- 18/129 The ODR provided a verbal update on the publication of the PHE Data Release Register and revisions to the register agreed by the Board to reflect the adoption of the Understanding Patient Data (UPD) terminology for “spectrum of identifiability”.

- 18/130 The ODR noted that the UPD terminology has now been adopted; however, publication of the first 2 quarters of 2018/2019 register had been delayed while clarification was sought on the NHS Digital policy on the declassification of date of death as a direct identifier. The Board noted that the responsibility for controlling access to civil registration data (birth and death data) has passed from the Office for National Statistics to NHS Digital.
- 18/131 The ODR raised concern that different data controllers will be classifying the level of identifiability of the same datasets differently and that it was unclear if the national opt out is being applied by NHS Digital to data releases that contain no other direct identifiers than date of death. The published data release registers denote releases including date of death to be “personally identifiable”. The Board were asked to comment on how the ODR should resolve changes to the interpretation of date of death and if such changes should be applied either prospectively and/or retrospectively.
- 18/132 The Board agreed that further reflection was required on ODR release practices and that NHS Digital should be engaged to provide formal clarification on the scope of this change to ensure that messaging to the public is consistent and PHE appropriately upholds the national opt out.
- 18/133 **Action:** Professor John Newton to write to NHS Digital to request clarification on the declassification of date of death and how NHS Digital will communicate this change to the public.
- 18/134 The ODR noted that the declassification of date of death would reduce the number of applicants, which are prompted to seek an exemption to process personal confidential data without consent. It is currently unknown what exit strategies current data recipients will need to present to the Confidentiality Advisory Group.
- 18/135 **Action:** The ODR to liaise with the Health Research Authority, Confidentiality Advisory team for clarification on how ODR should advise data recipients on the declassification.

Any other business (AOB)

Change of disclosure for Hospital Episode Statistics (HES) data

- 18/136 The Board noted that NHS Digital had published revisions to the Hospital Episode Statistics Analysis Guide that alter the suppression methodology that must be applied to reporting of small counts at sub-national geographies (Regional, Area Team (AT), Commissioning Region (CR), LSOA, MSOA, CCG, GP Practice, Trust, Provider etc.). The impact of this change was discussed and the Board noted that PHE Policy for handling small numbers when releasing aggregate statistical data is now disharmonious with the guide. It was noted that PHE had not been informed of this change prior to publication and changes in the permissible threshold for reporting small counts from 5 to 7 (including the need for statistical rounding) could negatively impact how PHE ensures the public health workforce have appropriate data to act upon through indicators and the Public Health Outcomes Framework (PHOF).

- 18/137 The Board expressed their discontent with the changes and expressed that they would like more information on what consultations exercises were conducted by NHS Digital prior to deploying this change.
- 18/138 **Action:** The Board agreed Professor John Newton will write to NHS Digital to raise concerns about the deployment of changes to the Hospital Episode Statistics Analysis Guide with NHS Digital; including the need for cross-organisational consultation and the impact on current open data publications.
- 18/139 **Action:** The Board agreed that the Chief Clinical Information Officer will escalate this change internally to the PHE Policy for handling small numbers when releasing aggregate statistical data policy owner.
- Next meeting of the Data Release Assurance Board*
- 18/140 The next meeting of the Board is scheduled for 19 February 2019. A call for agenda items and papers will be circulated with the draft minutes.
- 18/141 No further updates were made to the Board.

Actions summary table:

| Item # | Action | Action owner |
|---------------|---|------------------------------------|
| 18/105 | The Board agreed to provide feedback through to the Joint Working Group on the variable benefits and needs of users. Feedback to be provided directly to the Chief Clinical Information Officer. | Chief Clinical Information Officer |
| 18/106 | The Board agreed that the Joint Working Group should include within the scope of each business case a cost-benefit analysis, which identifies the strategic benefits of transferring data controllership of specific data collections to NHS Digital. | Chief Clinical Information Officer |
| 18/113 | ODR to provide secretariat support to the IAPDR Chair to commence recruitment to the Independent Advisory Panel on Data Release. | Office for Data Release |
| 18/121 | The Board recommended that the Caldicott Guardian function should revisit the staffing costs outlined in the paper to ensure resilience to deliver the 6 recommendations outlined in the Review. | Caldicott Guardian Function |
| 18/127 | The ODR to produce an exception report detailing instances where data was not disseminated within 60 working days of a complete application and to present this report to the Board at the next Data Release Assurance Board meeting. | Office for Data Release |
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