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

Date	12th July 2016	
Time	14:30 – 16:30	
Venue	Room 201A, Skipton House	
Present	John Newton	Chief Knowledge Officer & SIRO (chair)
	XXXX	Consultant in Public Health Strategy at Public Health England & Deputy Caldicott Guardian (HP Protection)
	XXXX	National Director for Disease Registration & Deputy SIRO
	XXXX	IG advisor
	XXXX	Head of Public Health Data Science
	XXXX	PHE lead for Official Statistics
	XXXX	Data & Information Policy and Partnerships Lead
	XXXX	Lead for the National Drug Treatment Monitoring System & Clinical Information Officer
	XXXX	Head, Office for Data Release
	XXXX	ODR Senior Project Manager (secretariat)
Apologies		

1. Introductions and apologies

16/001 The chair welcomes members of the Board. No apologies were received.

2. Minutes of the previous meeting

16/002 The minutes of the 18th February 2016 meeting were approved by the Chair.

3. Matters arising

16/003 JN met with Paul Cosford and Derek Crook. It was noted that they are both supportive of broadening the scope of the ODR to cover all releases of data to third party stakeholders. They further acknowledge the need to pool expertise where feasible to do so.

16/004 The ODR is working with colleagues in PHE Digital to develop a gov.uk web presence. Copy for this site is now in draft and pending approval from PHE Gateway. It was agreed that the ODR should

aim to have this publically available by August 2016.

16/005 Members were invited to comment on the membership of the DRAB. It was agreed that there needed to be engagement with NIS and an invitation to join the DRAB should be extended to XXXX.

16/006 Questions were further raised about the inclusion of a Non-executive director and the inclusion of lay members. XXXX explained about the role of the PHE People Panel and the Board recognised the inherent value of independent membership.

16/007 PHE's Advisory Board in September[1] will focus on the disclosure of data to support local government in enacting their delegated public health functions. It was agreed that this platform should be utilised to discuss PHE's broader role as a data custodian.

4. PHE Internal audit

16/008 An internal audit was conducted to look at PHE management of data and its compliance with relevant regulations, including safeguards in place to manage information held by PHE and the processes in place to manage the dissemination of data to third parties.

16/009 A final audit report has now been received by the Accountable Officer and is available for distribution. A summary of the findings of the report were reported, as follows:

a) Overall PHE received a 'limited' rating - there are significant weaknesses in the framework of governance, risk management and control such that it could be or could become inadequate and ineffective.
b) The review has made 8 recommendations concerning the management of information and the release of data.
c) ODR was recognised as good practice and the report proposes the extension of the ODR's remit to cover all PHE.

16/010 The report will be circulated to members and a PHE Management Committee response will be drafted.

16/011 The Board discussed the adequacy of the ODR's current resource to extend the ODR function to all PHE assets and the interaction with the Caldicott Guardian network and Caldicott oversight group, chaired by the Deputy Caldicott Guardians.

The Deputy Caldicott Guardians explained that the goal of a CG oversight group is to have a more strategic function, with more agile advisory function operationalised at divisional and/or departmental level though the associated CGs. Similarities were drawn from IGARD and the UK Biobank Ethics and Governance Framework

[1] Since postponed to November

model

16/012 The ODR reiterated that all releases of personal data must be approved by the Caldicott Guardian function. It was agreed that the inter-relationship between the ODR and this function needs to be fully documented, accountable and auditable. Best practice should be drawn from the UK Caldicott Guardian Council (UK CGC).

5. Regulation 3 processing

16/013 Regulation 3, provides a legal basis to process confidential medical information relating to communicable disease and 'other risks to public health'. It is clear that this regulation is intended to cover more than communicable diseases; however, 'other risks' are not explicitly defined in the regulations themselves. It was noted that Regulation 3 is not restricted to surveillance activity alone but details high level clusters of processing activities. These are class versus project specific and not all acute risks.

16/014 The Board considered the decision-making process outlined in the paper for PHE to determine if it can rely on Regulation 3 to support processing of confidential medial information to support its activities relating to 'other risks to public health'.

16/015 It was noted that there are ongoing discussions regarding amendments to the Health Services (Control of Patient Information) Regulations within the DH.

16/016 The Board recommends the implementation of a Regulation 3 approval model akin to section 251 support and the annual review of current data processing activities under Regulation 3. Questions were raised over the inclusion of a position statement in PHE's response to the National Data Guardian report and whether to legitimise the agreed approach, a public consultation should be launched. It was further agreed that the Accountable Officer should be engaged regarding this corporate risk.

16/017 The Board agreed to formally develop PHE's approach to Regulation 3 activity through the Caldicott Guardian. A standard operating procedure should be drafted in collaboration with colleagues in the Information Governance Office and ODR.

16/018 The Caldicott Guardian to initiate a review of current Regulation 3 processing activities, to ensure a definitive list of processing under this gateway and to document which sub-header of the regulation, each processing activity pertains to.

16/019 Once PHE's approach is ratified, PHE should consider publishing a statement of policy and sharing approach through peer reviewed journals

6. The National Data Guardian report

16/020 A paper was presented by the Information Governance Office, alongside the published National Data Guardian report. It was noted the Information Governance Office will collate responses from

colleagues across PHE to support a corporate level response. A provisional response will be shared with the deputy Caldicott Guardians ahead of final submission.

16/021 It was noted that PHE has been supportive of an overlapping review of patient consent by the cancer charities. NCRAS recognises the need to reflect upon the outcomes of this review and refine the information offered to cancer patients and ensure the fair processing notice wording is fit for purpose.

16/022 It was noted that PHE recognise the inherent importance of upholding Type 2 objections. Discussions with the HSCIC have proved futile and they are not interested in supporting the removal of Type 2 of objectors unless acting upon a binding directive from the Department on behalf of the Secretary of State.

7. Identifiable data released by ODR

16/023 It was noted that only a very limited number of explicitly identifiable data releases had be made by the ODR. Releases of this nature are permissive where:

- explicit informed consent to access sensitive personal data is extant
- the disclosure is to support the direct care – returning data to the treating clinician
- under regulation 5 (section 251) where an exemption to the common law duty of confidentiality is awarded by the HRA acting on behalf of the Secretary of State.

16/024 All requests for direct care purposes must be endorsed by the applying organisation's Caldicott Guardian and this must be evidence in the application to the ODR.

16/025 ODR will continue to work with partners to limit the release of identifiable data and a statement on access arrangements will be published, detailing the partnership approaches (such as in house safe haven access) which should be utilised to limit disclosures of personal confidential data.

16/025 The Board were informed of the ongoing dialogue with LSHTM to update the linkage process for the vital work of the cancer survival group, to ensure the process minimises potentially identifiable data exchange by bring this linkage in house.

8. Development of the PHE small numbers policy

16/026 The Chief Statistician presented a draft corporate policy for the disclosure of small cell counts and statistical reliability. It was noted that senior analytical colleagues across the organisation had been engaged in the design of the policy, however there were mixed views on handling zero cell counts.

16/027 The Board discussed the need for a risk assessment and rule based approach to small cell disclosure to limit disclosure by inference and causing distress (i.e. where the patient can self-identify). It was

agreed that any policy should be underpinned by appropriate, audience specific guidance.

9. ODR cost recovery

16/028 The ODR presented a proposed cost recovery policy for services rendered by the ODR in the review, approval and release of data. The Board were supportive of implementation of full economic cost recovery, in line with HM Treasury rules for public sector bodies on the recovery of fees, charges and levies.

16/029 Concerns were raised regarding external facing communications, especially where data has been extracted for the stakeholder free from charge prior to the implementation date. It was agreed that a communication plan should be discussed with the Communications Office. The ODR will engage with PHE Communications team and colleagues in the Public Accountability team.

16/030 The Board discussed the wider application of the policy to assets currently not in the scope of ODR and other charging considerations (including fee waivers). It was noted that the model could be extended to other PHE assets, if there was the appetite to do so.

16/031 The Board request ODR implement cost recovery within 2 months of this meeting. Proposed for start of September.

10. ODR operational update

16/032 The ODR presented a summary of ODR performance from 1st April 2015 – 31st March 2016. It was noted that there has been a significant increase in ODR throughput.

16/033 ODR had responded to 244 project-specific enquiries, in addition to 130 applications. Over 70 releases of data were made during the period.

16/034 The Board questioned if any softer metrics were being recorded and urged the ODR to develop clear feedback mechanisms to support qualitative assessment of performance. ODR noted that an external communications plan was in draft and feedback mechanisms feature prominently.

11. AOB

16/035 It was noted that NHS England has appointed a new Chief Clinical Information Officer.

16/036 It was agreed the next meeting would be held in October 2016. Details of the meeting to be circulated with the chair approved minutes. Post meeting note: next meeting to be 4th November 2016.

Actions:

Item #	Action	Action owner
16/004	ODR webpages to be launched by August 2016 on Gov.UK	ODR
16/005	XXXX to be invited to join the DRAB membership	Secretariat
16/010	A copy of the final Internal Audit of Data Sharing report and response from the Management Committee to be circulated to the DRAB	IGPO
16/016	SIRO to liaise with the Accountable Officer regarding PHE's risk appetite in regards to the use of Regulation 3 and proposed structured approach to handling requests under this legal gateway	SIRO
16/017	Draft SOP for handling requests to process data under Regulation 3 to be presented to the Data Release Assurance Board via the Caldicott Function	Associate CG
16/018	Associate CGs to recommend to the PHE Caldicott Guardian that a review of current Regulation 3 processing activities, to ensure a definitive list of processing under this gateway and to document which sub-header of the regulation, each processing activity pertains to, should be initiated by the Caldicott Guardian function.	Associate CG
16/031	ODR to implement cost recovery policy and agreed composite rate with communications support from the PHE Communications and Public Accountability Teams.	ODR