Public Health England

Minutes

Title of meeting	Data Release Advisory Board
Date	18 February 2016
Time	14:00 -16:00
Venue	LG2, Wellington House
Attendees	John Newton (Chair) (JN) XXXX XXXX XXXX XXXX XXXX XXXX (Secretariat) XXXX XXXX
Apologies	XXXX

1. Introductions and apologies

1.1. Professor Newton introduced and welcomed XXXX to the membership of the Board.

1.2. Apologies were noted from XXXX.

2. Minutes of the previous meeting and actions

2.1. The Board reviewed the minutes of the previous meeting and they were approved as an accurate reflection of the meeting.

Actions for the previous meeting:

Action	Responsibility of
Professor John Newton to write to Duncan Selbie with a formal recommendation on behalf of Board regarding the implementation and resourcing of new governance structure for activity under Regulation 3.	JN wrote to Duncan Selbie on behalf of the Board documenting their recommendations. It was agreed that JN would write to Duncan Selbie again following on from the outcome of the Caldicott 3 review.
XXXX to conclude work on the interpretation of Regulation 3 and present for adoption by the new governance structure.	Item scheduled for discussion (Item 3)

Members of the Board to provide feedback on the content of the ODR standard operating procedures (Approval process and Data Release Register) by 31st October (or two weeks following the dissemination of the minutes.	All – complete and now live.

2.2. The Board further discussed a number of actions still live from earlier meetings:

Disclosure control policy working document to be circulated to XXXX for comments on whether PHE should adopt an existing policy or establish new controls	A paper was circulated prior to the departure of XXXX however there has been no further action on this. It was proposed that this should be progressed through XXXX in role as Chief Statistician.

2.3. It was recognised the HSCIC Anonymisation Standard was not always stringent enough (K3) for PHE's purpose(s). The Board discuss the need for a pan-PHE policy that takes a risk-benefit approach to small numbers and deductibility. It was agreed that XXXX present this to the next Board (July 2016). The policy should be published on the IG microsite.

2.4. In the absence of a policy, a statement should be agreed to enable submission for IG toolkit level 2. XXXX highlight the need for evidence of understanding of the risks associated will sparse cells and training gaps across the organisation.

Action(s):
XXXX to present to the Board a disclosure policy by the next meeting (July 2016).

3. **Update on stakeholder relationships and national initiatives**

3.1. XXXX presented a paper documenting the challenges faced by PHE in executing its statutory powers under Regulation 3 of the statutory instrument. 1438 – Health Services (Control of Patient Information) Regulations 2002. It was noted that many of the PHE disease registration and disease surveillance functions rely on data processed without consent under Section 251 (> 50 data collections).

3.2. Authority to process data under Section 251 is granted by CAG/HRA on behalf of SoS for purposes related to cancer registration (Regulation 2) and medical research (Regulation 5), and by PHE for purposes related to communicable disease and other risks to public health (Regulation 3). To ensure that PHE fully complies with the Regulation 7 requirement to review all uses of Section 251 on an annual basis, a formal procedure needs to be confirmed for use of Regulation 3 and implemented across the whole of PHE

to ensure that these processing purposes are assessed and reviewed against a common set of approval criteria.

3.3. A proposed operational and governance framework for the delivery of an approvals process and accountability of PHE's use of this statutory power was discussed. The Board agreed any approval to process personal data under Regulation 3 needs to be documented in a consistent way, and a central record of these approvals maintained, regardless of if the an internal use or and request received by PHE from external organisations. It is also paramount that there is clear cross-organisational policy and leadership on any processing activity using this statutory power.

3.4. XXXX explained that oversight of this statutory power is currently provided by a network of Deputy and Associate Caldicott Guardians across the PHE Directorates, which supports the Medical Director in the role of organisational Caldicott Guardian.

3.5. The Board further agreed there needs to be a high level interpretation of 'and other risks to public health', with exemplars not an exhaustive list of uses to build confidence in the owner/inspector role of PHE.

3.6. The Board agreed that implementation of a process should be within 3 months.

Action(s):
XXXX and XXXX to finalise the operational and governance frameworks to support the processing of data under Regulation 3
XXXX to work with the Caldicott network to validate the approach.
XXXX and the Information Governance Office to collaborate with the Caldicott Guardian network in the implementation of a consistent approach to handling processing of data under Regulation 3.
SIRO and CG to review the adequacy of the approach take.

4. Update on stakeholder relationships and national initiatives (TM)

4.1. The HSCIC has been instructed by DH to act on the Type 2 objections received following the care.data public information campaign. It is understood that 1,000,000 service users have dissented and await their opt out to be upheld by the HSCIC.

4.2. The National Data Guardian (NDG) for Health and Care has been asked by SoS to advise on a new national consent and objection model covering the whole of the health and care system (Caldicott 3 Review).

4.3. To ensure consistency between these two separate but related developments, the policy on Type 2 objections will not be confirmed by DH (in a formal Direction to HSCIC) until after the NDG report on the new consent model has been received by SoS.

4.4. It is expected that the NDG report will be presented to the SoS on Monday 22nd February. Following consideration by the SoS, it is expected that DH will undertake a public consultation. It is unlikely that any changes will be implemented until late 2016/17 at the earliest.

NB 04/04/2016: PHE are yet to be informed of a publication date for the NDG report.

Action(s):
XXXX to provide an update at the next meeting of the Board on the impact of Type 2 objections and the NDG report.

5. Update on the Ministerial Industry Strategy Group

5.1. An operational group has been formed with PHE, HSCIC and CPRD to explore the significant governance challenges in accessing combined data from a multiplicity of data controllers, including divergence in understanding of the Data Protection Act and process management for data access requests for research purposes.

5.2. Through the combined efforts of the operational group (HSCIC, CPRD and PHE), the Health Data Finder has now been launched as a stakeholder facing portal to understand the data available to researchers and to guide them towards the appropriate approval body. A link to the Health Data Finder was circulated with the agenda.

5.3. As an extension of this work, PHE is currently in the process of negotiating a data sharing contract with CPRD to determine the operational parameters within which CPRD can grant approval to researchers to process linked cancer registry data. This will allow CPRD to provide the single interface for access. Associated charges are under discussion.

5.4. During 2016, the MISG will look towards the creation of common pathways involving review processes led by the Health Research Authority and the data custodians.

6. Update on the Information Fair Trader Scheme report and action plan

6.1. A project officer was appointed to co-ordinate the response to the IFTS audit and a very constructive follow up meeting has been held with the Office of Public Sector Information.

6.2. Expectation is that the audit will be repeated and evidence presented in response to the initial audit will be used in PHE's IG toolkit self-assessment.

6.3. It was agreed that a formal letter of recognition regarding the development and use of the cancer simulacrum should contribute to the body of evidence to be submitted.

7. General update from Office for Data Release

A) ODR throughput

7.1. XXXX presented a summary report detailing ODR activity during the period 1st April 2015 to 31st January 2016 (Paper 3a)

7.2. During this period, the ODR has handled a total throughput of 330 projects (representing 28% increase in activity compared to the previous year). Total throughput is inclusive of 113 applications (up 68% of 2014-15). A limited number of these applications failed the ODR application validation criteria and were subsequently re-submitted. Since 1st April, 67 data releases have been made to ODR approved data recipients. A further 11 applications have been approved and pending release.

7.3. The Board were informed that requests for cancer registration data were currently limited to the 2013 registration year and that temporal coverage would be extended to the 2014 registration year in line with the start of the new fiscal year. There is also the intention to link the Systemic Anti-Cancer Therapy (SACT) to the CAS 2014 data. Questions were raised regarding access to SACT by commercial organisations and the Board was reassured that any release of cancer registration data must align to our statutory power to process the data (Regulation 2) and only be processed for "medical purposes".

7.4. The second Data Release Register was published on gov.uk on 15th February to reflect all releases made within the previous fiscal quarter.

7.5. CPRD requests – following the departure of the NCIN Data Manager, access to linked cancer registration data has been limited. XXXX noted that resource has now been found and ODR is working to resolve all issues to the flow of data to CPRD clients.

7.6. It was noted that the ODR has sought support from XXXX on appropriate workflow management to ensure that the burden of data extraction was managed within NCRAS.

B) Acknowledgement of authorship and collaboration

7.7. Following a request from the NCRAS IAO, the ODR has embedded the requirement for any professional and scientific contribution made by PHE employees to be appropriately recognised by Data Recipients.

7.8. The clause aligns to internationally recognised recommendations published by the International Committee of Medical Journal Editors – the ICJME Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals (ICMJE Recommendations 2013),The clause will appear as a 'special clause' and only be applicable to data available from the NCRAS.

7.9. The Board were asked for feedback on implementation of this contractual change. XXXX questioned if the text was stringent enough.

Action(s):
XXXX/XXXX to revise the text to ensure it is sufficiently robust to meet the needs of NCRAS

C) Expansion of the ODR

7.10. The Board reflected on the need to expand the remit of the ODR beyond current tri-directorate coverage and questions were raised regarding how National Infectious Services/ Health Protection were assuring themselves.

7.11. To explore extending the remit of the ODR or creating a parallel process for NIS/Health Protection Data, it was agreed that JN would meet with Paul Cosford and Derek Crook to discuss :

7.11.1. examples of best practice in data release,
7.11.2. known situations were processing has not been in accordance with best practice/ or concerns have been raised (XXXX and XXXX to contribute)
7.11.3. implementation of a cross directorate or parallel process to the ODR, and
7.11.4. the development of a business case to support the agreed implementation plan.

7.12. To support the discussions with PC and DC, the Board queried if there was any learning from the internal audit by the Health Group Internal Audit team. It was noted that this audit was expected to feed into the IG Toolkit submission. Clarity was sought on the current status of the internal audit.

Action(s):
JN to meet with Paul Cosford and Derek Crook to ensure that appropriate processes are in place to assure the SIRO of the legal and legitimate release of data.
XXXX to write to XXXX requesting an update on the Health Group Internal Audit.

8. Any other business (AOB)

MedConfidential

8.1. The Board were informed about evidence presented by MedConfidential to a Health Select Committee inquiry on the function of PHE. The evidence criticises the ODR for its lack of public web presence other than an e-mail address, a form and a guidance document on a page buried within the NCIN website.

8.2. XXXX agreed that there was validity in the comments and improving the visibility of the ODR to external stakeholders should be acted upon as an immediate priority. Content is in development. It was noted that any web presence will need to be carefully anchored across PHE webpages (i.e. Data Gateway) and link to the PHE privacy notice.

8.3. The Board were asked for assistance with the prioritisation of specific pages on the gov.uk website, as this had been difficult arrange via the PHE Digital Team.

Action(s):
XXXX to write to XXXX to seek clarity on who to contact within PHE Digital to

ensure the development of ODR content is prioritised.
XXXX to contact PHE Digital to ensure the prirtisation of the ODR webpages.

Implementation of cost recovery (TM)

8.4. A paper describing the use of a composite rate for all ODR applications will be submitted to the mid-March meeting of the Opportunities Assessment Group for approval.

Membership of the Data Release Advisory Board (All)

8.5. Members recognised that the membership of the Board needs to be extended to reflect non-CKO functions which undertake data release activity. It was agreed that an invitation to join the Board would be extended to XXXX (Director for the NHS Screening Programmes).

Action(s):
All to consider and feedback to JN individuals who should sit on the Board to strengthen accountability across PHE.

Next meeting of the DRAB

8.6. Confirmed for the 12th July, 14.30-16.30pm, 201A Skipton House.

Summary of all actions:	Responsibility
XXXX to present to the Board a disclosure policy by the next meeting (July 2016).	XXXX
XXXX and XXXX to finalise the operational and governance frameworks to support the processing of data under Regulation 3	XXXX/XXXX
XXXX to work with the Caldicott network to validate the approach.	XXXX
XXXX and the Information Governance Office to collaborate with the Caldicott Guardian network in the implementation of a consistent approach to handling processing of data under Regulation 3.	XXXX
SIRO and CG to review the adequacy of the approach take.	XXXX/XXXX/XXXX
XXXX to provide an update at the next meeting of the Board on the impact of Type 2 objections and the NDG report.	XXXX
XXXX/XXXX to revise the text to ensure it is sufficiently robust to meet the needs of NCRAS	XXXX/XXXX
JN to meet with Paul Cosford and Derek Crook to ensure that appropriate processes are in place to assure the SIRO of the legal and legitimate release of data.	XXXX
XXXX to write to XXXX requesting an update on the Health Group Internal Audit.	XXXX
XXXX to write to XXXX to seek clarity on who to contact within PHE Digital to ensure the development of ODR content is prioritised.	XXXX
XXXX to contact PHE Digital to ensure the prioritisation of the ODR webpages.	XXXX

All to consider and feedback to JN individuals who should sit on the Board to strengthen accountability across PHE.	JN