

# Update on the HSCIC's progress on implementing the recommendations from the data release review

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## Purpose

The purpose of this paper is to provide the HSCIC Board with an update on progress against recommendations made by Sir Nick Partridge following the *Review of Data Releases made by the NHS Information Centre*<sup>1</sup>.

## Background

In March 2014, the HSCIC undertook a review of Data Releases made by its predecessor organisation, the NHS Information Centre. The findings of this review were published on June 17<sup>th</sup> 2014.

In response to the review, and specifically to recommendations made by Sir Nick Partridge, the HSCIC Board introduced a series of steps to guarantee greater openness and reassurance to the public, stricter controls over data use and better clarity for data users. A programme of work was established to deliver these commitments with a target delivery date for the end of November.

On November 26<sup>th</sup> 2014, Sir Nick reported on his view of the progress made by the HSCIC in response to his recommendations. In this, he recognised that considerable progress had been made against most of his recommendations but that there remained areas for improvement, particularly in clearing the backlog of data requests and managing the tension between the ambition to improve health care for all and the need to protect people's privacy.

This paper provides an update of progress made against Sir Nick's recommendations since the end of November. Also included are the next steps planned for maintaining the direction of travel.

## Progress

### Overview of Progress

In the previous update to the HSCIC Board, strong progress was evidenced against five of the recommendations (recommendations 4, 5, 6, 7 and 9) and these can be regarded as having been delivered at the point of reporting with only minor elements, if any outstanding. Specifically, these relate to the requirement for greater transparency, improved processes and controls, record keeping and governance.

Progress against these five recommendations continues to be good, with further work having evolved out of these beyond the original agreed actions.

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<sup>1</sup> PwC for the HSCIC, *Data Release Review*, 2014 available at [http://www.hscic.gov.uk/media/14246/HSCIC-Data-Release-Review-PwC-Final-Report/pdf/HSCIC\\_Data\\_Release\\_Review\\_PwC\\_Final\\_Report.pdf](http://www.hscic.gov.uk/media/14246/HSCIC-Data-Release-Review-PwC-Final-Report/pdf/HSCIC_Data_Release_Review_PwC_Final_Report.pdf) especially pp. 71-74.

Four recommendations (1, 2, 3 and 8) however were identified as still requiring work. These recommendations relate to the deletion of data following the expiry of agreements; progress against the backlog of data requests; establishing a permanent audit function and implementation of secure access to data.

Work is still required on these as although they have progressed since November, they have not yet been completed.

Details of progress against each of the recommendations are provided below.

## **Alignment with additional HSCIC Commitments**

Following the Review of Data Releases and in response to Sir Nick Partridge's recommendations, the HSCIC board put forward a programme of work for positive change. These largely align with the work carried out in direct response to Sir Nick Partridge's recommendations, however additional update is provided where there is no one-one mapping. Further details of this are provided in Appendix A.

## Progress against recommendations from the Data release review

The information below provides a more detailed summary of progress against each of Sir Nick Partridge's recommendations. Also included are details of the next steps planned for progressing these and maintaining forward momentum.

### Recommendation 1

Recommendation	Action	Progress
<p>1) That the HSCIC undertakes a programme of work to ensure that data has been deleted appropriately for all data releases referenced in the PwC report, where the agreement has ended.</p>	<ul style="list-style-type: none"> <li>• Issue letters to all data recipients with Data Sharing Agreements (DSA) where the agreement has ended to confirm data deletion.</li> <li>• Review options to support customers in deleting the data.</li> <li>• Confirm data deletion complete.</li> </ul>	<ul style="list-style-type: none"> <li>• Deletion letters sent to:                             <ul style="list-style-type: none"> <li>• HES customers with expired agreements – 18/06/14</li> <li>• All other customers with expired agreements – 25/07/14</li> </ul> </li> <li>• 358 'Certificates of Data Destruction' received as of 14/01/15.</li> <li>• 221 requests for renewals or extensions to data have been received. If releases are approved, these will not require a data deletion certificate.</li> <li>• Additional resource has been brought in to support actively contacting customers by telephone.</li> <li>• A significant piece of work to review and cleanse the customer list is underway to ensure customers are not contacted erroneously. This is being re-visited in alignment with a recently commissioned project to ensure all relevant information held in Data Sharing Agreements is captured electronically.</li> <li>• Calls to customers commenced on 20/01/15.</li> <li>• Progress will be closely monitored as it is likely that there will be a significant number where data deletion cannot be confirmed owing to the age of the data release, organisational and structural change.</li> <li>• The Business as Usual process for data deletion for data released by the HSCIC has been built into new processes and resourced from within the contact centre. These processes are active and being managed.</li> </ul>

Next steps

- The data deletions team will work with the project team set up to review and input information held in live Data Sharing Agreements to ensure that customers are being contacted regarding the latest status of their data.
- Customers will be contacted directly via telephone w/c 19/01/15 to facilitate progress.
- Business as Usual processes for managing data deletion will be embedded into the new Data Access Request Service function once recruited to.

## Recommendation 2

Recommendation	Action	Progress
<p><b>2)</b> That the HSCIC develops one clear, simple, efficient and transparent process for the management of all data releases.</p>	<ul style="list-style-type: none"> <li>• Develop approach and specification for Data Access Request Service.</li> <li>• Identify existing re-useable components for integration.</li> <li>• Transition components and implement Data Access Request Service.</li> <li>• Provide simple intuitive access point for customers.</li> </ul>	<ul style="list-style-type: none"> <li>• Single access point for access to data (Data Access Request Service (DARS)) established.</li> <li>• Programme of work underway to ensure applications for primary care data, currently overseen by GPES IAG and those with separate governance processes are managed and tracked consistently through DARS.</li> <li>• Business as Usual structure for the Data Access Request Service (DARS) end to end process has been developed and is going through proposal for change processes. Roles from the temporary structure that directly match those in the permanent structure have been slotted in</li> <li>• Detailed operating procedures produced for each functional area involved in DARS.</li> <li>• Webpage providing single access point for access to data being reviewed and improved.</li> <li>• Clearance of Backlog progressing against revised target of 31/01/15.</li> <li>• Clearance of items currently in BAU (applications received between 01/08/14 and 31/01/15) forecast for 31/05/15.</li> <li>• Development underway to provide a web form to enable customers to complete applications online</li> <li>• A review is underway for options to facilitate online customer login and a progress tracker.</li> </ul>

### Next steps:

- Commence measurement and reporting on 30 day and 60 day Service Level Agreements upon clearance of the backlog (excluding current BAU data requests).
- Ensure BAU data requests cleared by 31/05/15.
- Implement web form for data request applications.
- Develop and implement options for an online tracking tool to enable customers to review progress on their own.
- Commence recruitment to all posts agreed for the Data Access Request Service.

## Recommendation 3

Recommendation	Action	Progress
<p><b>3)</b> That the HSCIC implements a robust audit function, which will enable ongoing scrutiny of how data is being used, stored and deleted by those receiving it.</p>	<ul style="list-style-type: none"> <li>• Identify resources to undertake audits.</li> <li>• Submit paper to EMT to agree approach.</li> <li>• Create framework, methodology and audit checklist.</li> <li>• Identify candidate organisations for initial audit.</li> <li>• Complete first wave of audits.</li> <li>• Develop approach and plan for full audit capability.</li> </ul>	<ul style="list-style-type: none"> <li>• Draft Audit framework and methodology developed.</li> <li>• First wave of audits completed on 02/09/14 for four organisations.</li> <li>• Full reports completed and under review.</li> <li>• Outcome of the audits and any associated follow up activities to be published on the HSCIC website following approval.</li> <li>• 4 further organisations identified for audit prior to March</li> <li>• 2x specialist audit roles approved and being recruited too.</li> <li>• An audit procedure including the criteria for undertaking an audit in development.</li> <li>• The HSCIC audit policy is being formally developed that will incorporate the above.</li> </ul>

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Next steps:

- Complete and roll out HSCIC Audit policy
- Complete recruitment of audit roles and implement permanent function
- Implement ongoing programme of Audits in line with policy.

## Recommendation 4

Recommendation	Action	Progress
<p>4) That the HSCIC publishes its policy, process and governance for the release of data.</p>	<ul style="list-style-type: none"> <li>• Incorporate learning from Partridge review into development of revised policy, process and governance.</li> <li>• Develop and implement revised policy and process.</li> <li>• Develop and implement revised governance arrangements.</li> <li>• Publish policy, processes and governance for release of data on HSCIC website.</li> <li>• Refine and update processes.</li> </ul>	<ul style="list-style-type: none"> <li>• Revised single process for all data access requests has been implemented.</li> <li>• Webpages went live on 31/07/14 providing simplified customer process (broken down to the 3 key steps of 'Apply, Approve and Access'). These webpages are currently being reviewed and improved to provide greater clarity around the processes.</li> <li>• Data dissemination rules developed and embedded into the data release checklist, which is being used to assess applications.</li> <li>• 1<sup>st</sup> draft of Data dissemination policy developed and in review cycle.</li> <li>• Review of Data Dissemination policy with CAG arranged for 15<sup>th</sup> February.</li> <li>• Programme of communications to update customers and staff about new processes and implementation of SLAs being developed for rollout at the end of January.</li> </ul>

### Next steps

- Incorporate changes to the policy in line with outcome of regulations to the Care Act 2014.
- Roll out Data Dissemination policy once approved.

## Recommendation 5

Recommendation	Action	Progress
<p>5) That the HSCIC ensures there is clear, transparent and timely decision making, via the appropriate governance for all data releases, and that all decisions are documented and published on its website.</p>	<ul style="list-style-type: none"> <li>• Develop transparent, clear process that is accessible to all users.</li> <li>• Document and publish all decisions from DAAG.</li> <li>• Recruit patient and public representatives to DAAG.</li> </ul>	<ul style="list-style-type: none"> <li>• Interim Data Access Advisory Group (DAAG) operational. Membership and frequency of meetings increased to support delivery of backlog.</li> <li>• DAAG recommendations published on HSCIC website.</li> <li>• Permanent function for Data Dissemination Advisory Group (DDAG), successor to DAAG being developed.</li> <li>• Data Publication and Dissemination Group (DPDG) being established to provide strategic overview of Data dissemination.</li> <li>• Views of the National Data Guardian being sought on the proposals</li> </ul>

### Next steps:

- Establish a design workshop with relevant stakeholders to develop recommendations for DDAG and DPDG.
- Refine proposals and seek final approvals within HSCIC and at Board level.
- Implement new arrangements as soon as possible during 2015 (noting that any external recruitment arrangements may take some time)

## Recommendation 6

Recommendation	Action	Progress
<p>6) That the HSCIC implements a robust record keeping approach and that the details of all data releases (including the purpose for which they are released) are made available on its website.</p>	<ul style="list-style-type: none"> <li>Enhance and unify existing data sharing 'trackers' for short term management of releases.</li> <li>Develop unified order management approach using Customer Relationship Management (CRM) system as single source of truth.</li> <li>Publish quarterly Data Release register.</li> <li>Complete transition to order management process across the organisation for management of all data requests.</li> </ul>	<ul style="list-style-type: none"> <li>Single system in place and being used to management of data access applications.</li> <li>Dashboard created for weekly reporting providing tracking and monitoring against progress.</li> <li>3rd iteration of HSCIC data release register published on 14/01/15 covering data release made between 01/07/14-30/09/14.</li> </ul>

### Next steps:

- Develop robust management reports and key performance indicators for monitoring and reporting progress
- Report performance against Service Level Agreements (measured for all application received from February 1st 2015).
- Automate production of data release register.

## Recommendation 7

Recommendation	Action	Progress
<p>7) That the HSCIC develops one Data Sharing Agreement (DSA), which is used for all releases of data, and which includes clear sanctions for any breaches.</p>	<ul style="list-style-type: none"> <li>Review and revise rules for Data Dissemination.</li> <li>Develop revised Data Sharing Agreement.</li> <li>Agree plan and approach for transition from current to revised Data Sharing Agreements.</li> </ul>	<ul style="list-style-type: none"> <li>Universal Data Sharing Agreement (DSA) and Data Sharing Framework Contract (DSC) rolled out. Templates published on the HSCIC website with supporting guidance.</li> <li>Requirements from Code of Practice on Confidential information being incorporated into DSC / DSA.</li> <li>Roll out of DSC's commenced on 24th October. Contracts sent to all existing customers with follow ups in December and January. Target for transitioning all customers to DSCs end of February. Additional resource has been brought into support this</li> </ul>

### Next steps

- Transition customers to new Data Sharing Agreement following roll out of Data Sharing Framework Contract.
- Implement function for monitoring and management of Data Sharing Framework Contracts.

## Recommendation 8

Recommendation	Action	Progress
<p>8) That the HSCIC actively pursues a technical solution to allow access to data, without the need to release data out of the HSCIC to external organisations.</p>	<ul style="list-style-type: none"> <li>• Develop scope and identify options.</li> <li>• Produce and publish road-map for provision of secure data access / data lab.</li> </ul>	<ul style="list-style-type: none"> <li>• 4 types of solution have been identified for enabling secure data access enabling access via: A secure data facility; federated hierarchy; secure remote access and public and open data.</li> <li>• HSCIC forum held with a wider range of stakeholders on 5<sup>th</sup> December introducing the above options in relation to secure data access, including the need for policy to determine criteria for secure access options.</li> <li>• A secure data facility is currently being implemented scheduled for completion in time for the care.data pathfinder stage in March 2015. This will be accessible to individuals with appropriate approvals who come to the HSCIC premises.</li> <li>• Separately, planning work is taking place to use the secure data facility for purposes beyond those of care.data</li> <li>• In recognition of the challenges and diversity of stakeholder views, a stakeholder reference group is being established to consult and advise on draft policy and requirements in relation to secure data access.</li> <li>• Engagement has commenced with ADRN and Farr to consider options for federated access.</li> <li>• Proof of concept for flexible public access to anonymised data has been refined and launch plans are being developed</li> </ul>

### Next steps

- Develop and implement policy on secure data access.
- Scope and develop options for wider uses of secure data facility.
- Align access requests with standardised processes developed through recommendation 2.
- Finalise and launch concept for public access to anonymised data.

## Recommendation 9

Recommendation	Action	Progress
<p><b>9)</b> That the HSCIC quarterly Register of all data releases includes the number of law enforcement agencies' person tracing requests processed by the National Back Office. The Register will also include all data being released under NHS IC data sharing agreements, ensuring it is providing a comprehensive account to the public of all data being shared.</p>	<ul style="list-style-type: none"> <li>• Publish number of law enforcement agencies' person tracing requests processed by the National Back Office (NBO).</li> <li>• Update quarterly register with data being released under NHS IC data sharing agreements.</li> </ul>	<ul style="list-style-type: none"> <li>• Data release register, incorporating number of tracing requests processed by NBO, published on 02/07/14. This register covered data releases made between 01/04/13 – 31/03/14.</li> <li>• 2<sup>nd</sup> iteration of HSCIC data release register published on 6/10/14 covering data releases made between 01/04/14-30/06/14.</li> <li>• 3<sup>rd</sup> iteration of HSCIC data release register published on 14/01/15 covering data release made between 01/07/14-30/09/14.</li> </ul>

### Next steps:

- Ensure capability exists to automate production of the register, enabling more frequent updates.

## **Actions Required of the Board**

For information only.

## Appendix A: Alignment of recommendations with HSCIC commitments

*1. Patients and public representatives will be part of the new membership of the HSCIC's data oversight committee, the Data Access Advisory Group (DAAG). This work will be overseen by the Confidentiality Advisory Group which will gain statutory powers later in the year.*

The Data Access Advisory Group (DAAG) was re-convened following the review of data releases to review individual data release requests and provide expert advice to the HSCIC about the requests including a recommendation about whether the request should be accepted or not. Membership of DAAG was strengthened with the recruitment of two independent expert members, external to the HSCIC. DAAG in its current mandate exists as an interim arrangement whilst the backlog of data requests is being processed. The second iteration of DAAG, the Data Dissemination Advisory Group (DDAG) is currently in development, with initial proposals having been submitted for approval. Included in this are proposals to recruit lay representatives to its membership.

*2. All data agreements will be re-issued, to ensure activity is centrally logged, monitored and audited, resulting in a clear and transparent process. Decisions will be documented and published.*

See update on Recommendation 7.

*3. A new, strengthened audit function will monitor adherence to data sharing agreements and halt the flow of data if there are any concerns exposed. This will also monitor that data has been deleted when an agreement comes to the end. Any failure on the part of data users to abide by their agreements will entail no further release of data to them.*

See update on Recommendation 3.

*4. A programme of active communication to the public and patients will help bring greater clarity about an individual's right to object to their data flowing to or from the HSCIC.*

A range of communications are planned to ensure the public and patients have greater clarity about an individual's right to object to their data flowing to or from the HSCIC. Included in this will be direct contact with all patients who have registered a Type 2 objection and wider communications with patients regarding their options as part of the Care.data programme. Additionally, the HSCIC has recently revised its public facing website pages (<http://www.hscic.gov.uk/article/3768/For-the-public>) to explain clearly what the HSCIC does

and how it will use patient information. Included in these pages is information about how individuals can object to the HSCIC using their identifiable data.

*5. A list of all active data sharing agreements will be published in the HSCIC quarterly register, including 14 which originated in the NHS IC. Numbers of all people tracing requests by law enforcement agencies will also be included.*

See Recommendation 9

*6. Working with partners through the National Information Board we will begin a public consultation and vision for a new national collection strategy for health, public health and social care data and report by May 2015 on its findings.*

The need for a new data strategy is a key theme in the new HSCIC corporate strategy, which will be published for consultation at the end of January. The HSCIC continues to work through the NIB and the relevant workstreams which are developing the plans for implementing the commitments in the NIB Framework for Action. The workstreams expect to produce more detailed plans by February 2015.

*7. The HSCIC will take forward its new responsibility to oversee NHS data security across the health and social care sector, to ensure best practice is followed and the most up-to-date technology is employed to protect patients.*

The HSCIC is currently managing a project commissioned by the Secretary of State which is looking specifically at Data Security across the wider health system. Over 40 tests are planned, or have been completed, in a variety of different organisation types and HSCIC will assess the results of these tests over the coming months. The output of these assessments will inform and drive the development of new data security standards, architectures and technology adoption as outlined in the NIB Framework for Action.

HSCIC has also now received approval from the Cabinet Office National Cyber Security Programme to run a number of national level projects until March 31st 2016 in support of innovative approaches to Cyber Security and incident management.

*8. The HSCIC will plan a new 'data laboratory' service which will protect the public's information by allowing access to it in a safe environment with HSCIC managed networks and facilities.*

See Recommendation 8.

*9. The HSCIC will work towards the externally assessed, highest industry standards of ISO27001 for data security and ISO9001, for data management, as part of its efforts to build public confidence.*

A Management Systems team has been established responsible for leading this business change and providing assurance (through the recently established Quality Council) that the HSCIC is making progress for the adoption of ISO 9001 and ISO 27001 (Information security).

Implementation has commenced, with all areas across the organisation requesting an initial baseline internal audit by 31<sup>st</sup> December 2015. Implementation will be phased across the organisation, with some areas having already achieved certification to ISO 9001.

Recruitment has commenced for permanent internal auditors to support the implementation of the ISO standards. This will be supported by training for ten part-time auditors drawn from existing HSCIC resource who will provide a minimum of two audits per annum. It is expected that these resources will be trained and ready to audit by 31<sup>st</sup> March 2015.

It is intended all areas of HSCIC will be certified to ISO 9001 and 27001 by March 31, 2017.

*10. The HSCIC intends to invite stakeholders to a meeting to discuss the implications of these actions and gain views about their effectiveness in helping maintain secure and trusted information systems on July 15.*

This stakeholder event was held on 21<sup>st</sup> July 2014.