



9<sup>th</sup> May 2014

Dear HSCIC Customer

I am writing to explain the actions the HSCIC is taking in order to review our processes for handling the release of data. I apologise for any delays or confusion that you are experiencing in relation to this issue which is complex and has significant implications for our customers and partners.

Access to health data is currently being widely debated publicly and placed under some parliamentary scrutiny. We are committed to answering any concerns raised, as well as ensuring we are operating to the highest possible standards for the secure handling of confidential information.

We are undertaking a comprehensive review of all policies, processes and governance for the sharing of data, which involves ensuring there are appropriate approvals in place for any release of potentially identifiable data. We want all these processes and decisions to be accessible to the public and open to scrutiny. We are also reflecting on the implications of legislation currently going through parliament with the Care Bill, which aims to add further protections for individuals, including their right to object to the indirect use of their data.

We have adopted an interim set of arrangements for managing the release of data, aimed at demonstrating our commitment to building public trust while we carry out this review. I am committed to working collaboratively on this – the health and care system requires us to do so. We are therefore in the process of setting up more detailed discussions with our customers and partners.

In anticipation of these discussions, the following interim arrangements have been implemented with immediate effect:

- For customers who are awaiting renewal of their data sharing agreements, these will be considered for renewal on a short term basis for between three and six months, depending on what type of data is being requested and for what purpose the data is required.
- For customers who have data sharing agreements in place, data releases will continue until the renewed policies, process and governance are implemented for new requests and renewals. We expect these to be in place by July 2014. We will then also initiate a process for all existing customers to apply again for a new agreement. This will be using a revised data sharing agreement, which will be designed to ensure that all parties have absolute clarity on their obligations with regards to the use of the data and the required controls.
- The Data Access Advisory Group (DAAG) will now provide independent scrutiny and review of applications, prior to making a recommendation to approve or reject an application. Requests for new data and requests for amendments to existing agreements that require additional data items will be processed following the successful processing of all other renewals.



We are also currently enhancing our audit capability by developing a function that in future will undertake audits of adherence to obligations within data sharing agreements, including security of data and the deletion of physical and logical data at the end of agreements.

Given the large number of agreements that exist, the process of taking all customers through the re-application process will take a number of months. However, we will work with you in a pragmatic manner during this time, and will continue to use short-term renewals as appropriate.

Should you wish to request an extension to the term of the existing agreement, please notify us in writing at [enquiries@hscic.gov.uk](mailto:enquiries@hscic.gov.uk) quoting in the subject line 'Data Ext Request'.

If your agreement has expired, and you do not wish to request an extension, under the terms of the agreement you are obliged to ensure that:

- Any data held is permanently deleted;
- Physical media is destroyed using a high specification shredder with the functionality to irreversibly destroy the disc;
- Any data held is also permanently deleted from any backup tapes that contain it;
- You confirm in writing to us that all data has been destroyed / deleted securely in accordance with the terms of your agreement.

While I recognise that this introduces some significant challenge for yourselves, I am sure you will agree that all of us need to work together to increase, rather than dissipate, public trust. Without public confidence it becomes impossible to deliver the full benefits from the analysis and insight which data can deliver. Thank you in advance for your cooperation in this extremely important matter. I will write again when we have further detail to share about proposed changes to applications.

If you wish to have a discussion about any of the points raised in this letter, please contact [enquiries@hscic.gov.uk](mailto:enquiries@hscic.gov.uk) alternatively call 0845 300 6016 selecting option 2.

Yours sincerely

Max Jones  
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