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Health & Social Care Information Centre

Review of data releases by the NHS Information Centre

Summary of HSCIC progress against the review recommendations

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Introduction

Six months ago I presented to my fellow Board members at the Health and Social Care Information Centre (HSCIC), the **Review of Data Releases by the NHS Information Centre**[1]. The Board had asked me to lead the review to meet a growing public demand for greater scrutiny of the way health and social care data is used.

The purpose of this report is to provide an update on the progress made against the recommendations accepted by the HSCIC Board and shared with both the public and MPs on the Health Select Committee.

I am glad to be able to confirm that considerable progress has been made on my recommendations and to provide details of some additional work that is being undertaken to ensure the HSCIC meets the highest standards the public expects. To earn the public's trust we have to make sure that people have ready access to understanding what uses their data is put to, as well as confidence in the processes used to approve or reject requests for data.

Before giving updates on my nine recommendations, I would like to cover some of the broader changes that are happening within the HSCIC as it responds to increasing public debate about the use of medical information to provide insight into health outcomes.

At the heart of this is the tension between the ambition to improve health and care for all and protecting peoples' privacy diligently. Most people would fully support research projects such as the Million Women Study[2] being conducted by University of Oxford and Cancer Research UK. The study, which by drawing on such huge numbers is significantly furthering understanding about any link between, for example, taking hormone replacement therapy (HRT) and the incidence of cancer. The women taking part in this study are fully aware of and consent to participate in this research, which is supported by the HSCIC providing data.

It is more complex when the data is being provided under safeguards, including legal ones, but not with the active consent of those who have contributed. I have been struck over the past six months that the HSCIC as a whole and staff within it are living this dilemma. Their awareness is acute of how crucial it is to maintain rigorous, centrally managed, fully documented processes, so decisions can be shared with the public.

At the same time, the support for researchers and research projects is a fundamental principle and staff are dealing with sometimes difficult discussions with data applicants. It appears to me they are behaving professionally while pushing themselves hard to meet both ambitions. This is part of a broader cultural change in which the commitment to transparency is embedding itself across the work of the organisation.

Sir Nick Partridge
Non-Executive Director,
Health and Social Care
Information Centre

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1   www.hscic.gov.uk/datareview

2   www.millionwomenstudy.org

Update on my recommendations for action

As set out in the detailed Appendix A, progress has been good on most of the recommendations. There remain serious issues with managing the backlog of data requests that has built up at the HSCIC, in part because more stringent checks and controls have caused delays in the provision of data. The expectation is that the backlog will be cleared and new service standards fully introduced by the end of January 2015.

I believe there has been a public shift in perception about the extent to which people expect to be informed and engaged about how their information is used. The insurance industry is an interesting example of this if we look at its response to expressions of public concern. The industry's use of data released to it by our predecessor body, the NHS Information Centre, was a catalyst for concerns expressed in the media and elsewhere that organisations might potentially misuse private medical information to either target individuals with advertisements or adjust their premiums.

Some in the industry were initially defensive when the HSCIC Chief Executive, Andy Williams, wrote to three companies involved in insurance in June asking them to voluntarily delete the data they held legally, ahead of legislative change. Discussions continued and minds have changed. The companies not only recognise they can use anonymous data to produce the analyses they want, but also that they want to reassure the public that they have no intention of misusing private information. The determination with which the HSCIC has pursued this matter has played a part in shifting the terms of the public debate. And the reaction of the industry is illustrative of the fact that both data applicants and those of us providing data have rightly been prompted by public concern to scrutinise more acutely whether each and every release is necessary and justifiable. It is important that the HSCIC continues to contribute to this as all organisations need to place proper importance on safeguarding private information.

Six investigations have been separately instigated by the HSCIC or Information Commissioner's Office (ICO)[3] and shared with both parties as these focussed on whether individuals were at risk of being identified. In the cases it has investigated, the ICO has upheld the HSCIC approach and informed us that it has "seen no evidence to suggest that re-identification has occurred or is reasonably likely to occur."

The Board will also recall that back in June I had to report that nine university research studies had been suspended as a result of the review carried out by PricewaterhouseCoopers. The review had discovered that after a change in the law in 2008, which required some studies to reapply for legal permission to receive data, nine had not done this. These nine long-standing studies were still receiving data from the HSCIC and were immediately suspended while the researchers applied for the permissions they needed.

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3   http://ico.org.uk

Since then the HSCIC has introduced more stringent checks to ensure that long-standing studies, some of which have been running for decades, have the correct, up-to-date permissions in place. No data is released to such studies without checks being carried out by four different members of staff to ensure that all the necessary safeguards have been met. This has led to the HSCIC identifying problems with the legal permissions for nearly 30 cases. We have made further suspensions in these cases and have worked with the projects affected to ensure they apply for the correct approvals so that, where the safeguards are met, data can flow again into vital research studies.
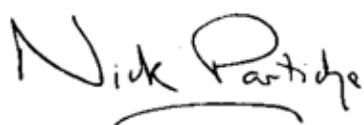
The final area of work I will cover is the review that the HSCIC has launched into the work of the National Back Office (NBO). The NBO primarily helps clinicians to identify patients quickly, easily and accurately so that when a doctor is making important decisions about, for example, a Mr John Smith, they can be confident they have the right Mr John Smith's medical details in front of them.

While this work forms the bulk of the work of the NBO, it also responds to tracing requests from law enforcement agencies who are trying to track down individuals. This aspect of NBO activity took place under the NHS Information Centre and was covered in the review published in June. The trace service continues to be operated at the NBO under the HSCIC and, as I recommended five months ago, the numbers of data releases to assist with tracing are now published in the register of data releases which is published by the HSCIC on a quarterly basis. The most recently published register shows that between April and June this year a total of 1,078 requests were received from the police, National Crime Agency, Home Office UK Immigration and the courts. Of these, 965 were approved as acceptable within NBO rules and traces were successfully carried out for 682 of these.

Before the review was published in June, this aspect of the NBO's work had received little public attention. In recognition of the wide range of views expressed, the Board is undertaking a review of the tracing service, chaired by Maria Goddard, a non-executive member of the HSCIC board, Professor of Health Economics and the Director of the Centre for Health Economics at the University of York. The review will look at the checks and balances in place to assess requests, the utility of the service to law enforcement and the concerns of those who object to health data being used for this purpose.

Conclusion

When the Board asked me in March this year to lead the review, my hope was that it would be a catalyst for positive change at the HSCIC, helping us to fulfil the vital role I believe we play on behalf of patients and service users. I was determined we would learn from the findings and take action as a consequence. Although there has been substantial progress, there is clearly more to do and the HSCIC is committed in its determination to do so. We have the opportunity to be part of an important change which secures huge advancements in health and care, while ensuring no surprises for the public about the use of their information.

Sir Nick Partridge
Non-Executive Director,
Health and Social Care Information Centre

Appendix A

Summary of HSCIC progress against the recommendations in the Review of Data Releases by the NHS Information Centre – 26 November 2014

Recommendation 1

That the HSCIC undertakes a programme of work to ensure that data has been deleted appropriately for all data releases referenced in the PricewaterhouseCoopers report, where the agreement has ended.

Progress

- Within a month of the publication of the review in June, we had contacted 542 data recipients who had 4,167 Data Sharing Agreements with the NHS Information Centre that had expired.

- As of 11 November 2014, we had received 335 Certificates of Data Destruction from 127 organisations. 68 organisations have applied for extensions or renewals to their agreements for data and therefore have not supplied certificates of destruction.

- Work is on-going to follow up with organisations which still need to provide evidence that they have deleted data. In some instances, for example, where an organisation has a long-expired agreement, is no longer in existence, or has restructured, it will prove challenging to close down all of these cases.

- Senior business analysis resource has been brought in to develop the approach to accelerating progress. Additional temporary resources have been reassigned from other parts of the HSCIC to support the approach and to work with customers.

- We have built specific controls relating to data destruction into the new end-to-end process for managing data applications, developed in response to the second recommendation (below). This new process will ensure the deletion process is checked as a matter of course for all data recipients as soon as their contract expires.

Recommendation 2

That the HSCIC develops one clear, simple, efficient and transparent process for the management of all data releases.

Progress

- We have set up a single point of contact for the management of data access applications: the Data Access Request Service (DARS). Details of the DARS process are published on our website at www.hscic.gov.uk/dars. A programme of work has been established to ensure that applications for primary care data, currently overseen by the General Practice Extraction Service Independent Advisory Group, and those with separate governance processes, are managed and tracked consistently by the DARS service.

- A single application form, data sharing contract and data sharing agreement have been developed, along with supporting guidance notes, and are available on our website at www.hscic.gov.uk/dars. The new contract and agreements are covered more fully in the progress report on recommendation seven (below).

- The stricter governance controls and more stringent quality checks undertaken before data is shared have contributed to a backlog of applications. We understand that this has caused frustration among researchers and others who need health and social care data in their work. We have put a specialist team in place to reduce this backlog and have also implemented new communications channels to keep applicants updated, including a fortnightly bulletin and dashboard that is published on our website at www.hscic.gov.uk/dars.

- We are projecting that the backlog, which includes all applications made before 1 August 2014, will be cleared by the end of January 2015. New service level agreements for applications will also be fully implemented by the end of January 2015 which range from:

  – 14 days for simple applications (such as extensions to existing approved applications) to

  – 60 days for the most complex applications (such as new applications for bespoke products).

Recommendation 3

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.

Progress

- We have started a programme of audits to check that data recipients are keeping patients' data confidential and safe, as they are required to do as a condition of receiving patient data. We have carried out four audits and expect to conduct at least 25 audits in the next calendar year.

- Learning from the initial audits is being embedded into the design of the new audit process. This has been an essential process for developing what is a complex area.

- The outcome of completed audits will start to be published on our website from the end of December 2014.

Recommendation 4

That the HSCIC publishes its policy, process and governance for the release of data.

Progress

- We have implemented a revised single process for all data access requests overseen by the new Data Access Request Service (DARS). Details of the new process have been published on our website at www.hscic.gov.uk/dars.

- The overarching criteria against which a request is assessed are published on our website at www.hscic.gov.uk/dars. These criteria will be further developed when the Care Act regulations are published and in response to advice from the Health Research Authority Confidentiality Advisory Group (HRA CAG).

- A new group is being formed to provide additional oversight and guidance on the HSCIC's data release policy – the Data Publication Dissemination Group. This group is expected to be in place by March 2015.

Recommendation 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.

Progress

- Membership of the Data Access Advisory Group (DAAG), the key HSCIC body that makes recommendations on applications for HSCIC data dissemination, has been strengthened to provide greater levels of expertise and independence. Four out of six members are now independent of the HSCIC, as detailed on our website at www.hscic.gov.uk/daag.

- The frequency of DAAG meetings has been increased to provide support to help clear the backlog of data applications.

- All requests received by DARS for data that could potentially identify individuals now go through DAAG and its recommendations are documented on our website at www.hscic.gov.uk/daag.

- The Acting Chair of DAAG, the HSCIC's information governance clinical lead, is engaging with HSCIC colleagues and key stakeholders to further strengthen and develop the DAAG role. In the future, it may have a role in providing strategic overview for the governance of data dissemination. Proposals under consideration also include:

  – broadening membership to include external, independent experts and advisers drawn from different fields of knowledge and expertise

  – the extent to which DAAG as an expert group should provide advice and guidance to HSCIC on its policies, procedures and approach

  – how DAAG should best organise its resources to process applications as efficiently as possible.

- All applications requiring permission to receive identifiable data from the Health Research Authority's Confidentiality Advisory Group (HRA CAG) continue to be referred to that body by the HSCIC as appropriate. Details of its decisions are documented on the HRA website[4].

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4   www.hra.nhs.uk/about-the-hra/our-committees/section-251/cag-advice-and-approval-decisions/

Recommendation 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.

Progress

- We have set up a single point of contact for the management of data access applications: the Data Access Request Service (DARS). Details of the DARS process are published on our website at www.hscic.gov.uk/dars.

- A Customer Relationship Management system (CRM) is in place and being used to track DARS data requests.

- We publish a quarterly data release register which details all releases of data made under a data sharing agreement. This includes the organisations that have received data, the type of data (for example, whether it is hospital, mental health, workforce data), the legal basis for sharing and the purpose for which the data was released. There has been considerable public scrutiny of the registers, demonstrating that this information is playing an important role in meeting the demand for greater detail on how people's data is shared.

Recommendation 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.

Progress

- A new data sharing contract (DSC), data sharing agreement (DSA) and guidance notes have been developed and are available on our website at www.hscic.gov.uk/dars.

- Each organisation is required to sign a DSC which sets out the overarching principles of data sharing between the organisation and the HSCIC. Each individual instance of data sharing will then be covered by a DSA.

- These documents make clearer to applicants:

  - the level of security they must have in place

  - the requirement that they use data only for health and social care purposes or the promotion of health

  - that solely commercial purposes are not acceptable

  - our right and intention to audit use of data; and

  - their duties to delete data.

- The process of moving existing data recipients over to the new DSC has started and we expect all customers to have transferred to the new DSC by the end of February 2015.

- Once existing data recipients have signed the new DSC, each one will be taken through a reapplication process to ensure that their proposed use of data is compliant with new legislation and they agree to the more stringent levels of scrutiny that we now require.

Recommendation 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.

Progress

- A consultation exercise was conducted from July to September 2014 on potential models for secure data access. Nearly 200 responses were received to an online survey and 34 interviews were conducted with key stakeholders. The results demonstrated that for some data recipients, technical solutions for accessing data without release would be of high value, while others (around a quarter) responded that secure online access would be of no or limited value.

- Four potential solutions have been identified for enabling secure data access. These are:

  – A secure data facility – a secure physical environment, based in Leeds, where authorised users will be able to access the data.

  – A federated hierarchy – a partnership that exists across two or more organisations to provide a network of secure data facilities, whereby data remains in the HSCIC but can be accessed from these secure settings.

  – Secure remote access – this enables virtual access to data remotely and securely, with data remaining in the HSCIC.

  – Public and open data – this enables a wide range of people who need to use data to 'self-serve' and look at anonymised information rather than needing to request bespoke data.

- A secure data facility is currently being implemented and is scheduled for completion in time, initially to support the care.data pathfinder programme.

- Work is also being undertaken to develop a public and open data system, to allow 'self-serve' of anonymised data. It is expected that a significant proportion of requests to produce bespoke aggregated outputs could be diverted to this self-service model in the future.

- A more detailed requirements gathering exercise will be completed on secure remote access by March 2015, with plans to implement a new remote secure access service by December 2015 for some data sets.

- The policy outlining the criteria for access, the circumstances under which it would replace issuing physical extracts of data and to whom it would apply is also in development. The first iteration of this policy will be presented for discussion at a stakeholder event in December 2014.

Recommendation 9

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.

Progress

• Our quarterly data release register includes all instances of data sharing under a Data Sharing Agreement. The data release register is published on our website at www.hscic.gov.uk/dataregister.

• The register now incorporates tracing requests made by law enforcement agencies.