Your Personalised NHS Data Usage report

produced for you by the HSCIC, available electronically via your GP
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News for you

As custodian of your, and millions of other NHS patients' confidential medical information, we the Health and Social Care Information Centre (HSCIC) believe you should know how your information has been used, and by whom, and what resulted from that use. Our aim is to build confidence by providing knowledge. This report therefore itemises who has accessed your data, and for what reason, in the past 3 months.

High quality information about illnesses, treatments and outcomes is hugely valuable. It is vital for planning and monitoring, for research, and to help run and improve the services on which we all depend. You have the right to choose whether your information is used for any purpose beyond your direct care. We hope this and future reports show how beneficial choosing to be included can be, and that knowing how your information is used begins to support your ongoing confidence in allowing your data to be used for those purposes. Choosing to be included is a gift from you; yours to share or not, as you decide.

Research conducted over the last 40 years has resulted in a new drug being approved for the effective treatment for relapsing multiple sclerosis. This project has used medical data collected from hospitals and GP practices to conduct trials and measure safety. The research team at Cambridge University will continue to monitor data into the future to ensure the drug's safety.

Using tools derived from research, commissioners, researchers and GPs are now able to identify groups of patients at high risk of heart disease and other long-term conditions. Your GP can now identify and offer appropriate advice to you, if you would benefit from an appropriate intervention. We are currently supporting a study looking at the effect of vaccines, by manufacturer and age at administration, based on this data. Any approval will appear in the next report (at the earliest) and first results will be published around a year after that.

We have moved into a wider phase of access to the new secure data facility that will protect everyone's information by only allowing access to patient-level data in a safe environment. The first use of this facility has been for the 4 areas which are care.data pathfinders; data extracted from GP systems under the care.data programme will only be accessible via the secure data facility. As our capacity to provide access to approved researchers in safe settings expands, the number of ongoing releases (page 9) will reduce towards zero.

In the past several months, HSCIC has re-issued all data agreements to ensure that every use of patient data is centrally logged, monitored and audited. Once companies have signed these new contracts, the recipients of any non-published data will appear in this report to you. In future, all such analyses will be required to be conducted in a safe setting. Any failure on the part of data users to abide by their agreements will mean no further release of data to them, and we will monitor that all data has been deleted when an agreement comes to the end.

We take our responsibility for looking after your medical information very seriously. If you have questions or concerns, we want to hear them.

(not quite the) Chief Executive
HSCIC

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Direct Care Accesses

From participating institutions[1], your medical record was accessed since 1st July 2014 at:

15th September 2014:
Your GP practice, Coventry.

11th, 13th September 2014:
LTH Pathology Ltd

10th-13th September 2014:
Leeds Teaching Hospital.

9th-10th September 2014:
York Hospital, including SCR via non-consented A&E.

3rd August 2014:
Your GP Practice, Coventry

There have been no reported breaches or losses of your medical records from your doctors or hospitals this quarter.

[1] for details and an explanation http://www.hscic.gov.uk/whoaccessedyourdata

Knowledge Created with your contributions

Your data is distributed as part of Hospital Episode Statistics (HES). Academics and researchers use them to try and learn more about health and illness. The research below may have been conducted in any of the last several years, on any health event since 1988 - when HES was first collected. You may have been included as a healthy person unaffected by the condition, as part of a comparison group to examine differences to the general population.

Two papers in the list below are Open Access, free to all. To read every paper in the below list would cost you £101.95 + $119.95 (some articles can't be purchased in pounds) plus the cost of 2 articles that won't reveal prices. To read all publicly available scholarly papers that used HES data, and search by keywords, please see http://www.hscic.gov.uk/whatwelearnt

Knowledge from Academic Research

A Time Series Evaluation of the FAST National Stroke Awareness Campaign in England
(Open Access: Free to all)
D Flynn, GA Ford, H Rodgers, C Price, N Steen… - PloS one, 2014 - dx.plos.org
Phase one had a statistically significant impact on information seeking behaviour and emergency admissions, with additional impact that may be attributable to subsequent phases on information seeking behaviour, emergency admissions via GPs, and thrombolysis activity. Future campaigns should be accompanied by evaluation of impact on clinical outcomes such as reduced stroke-related morbidity and mortality.

Impact of centralising acute stroke services in English metropolitan areas on mortality and length of hospital stay: difference-in-differences analysis **(Article cost: free to read)**
S Morris, RM Hunter, AIG Ramsay, R Boaden… - BMJ, 2014 - bmj.com
A centralised model of acute stroke care, in which hyperacute care is provided to all patients with stroke across an entire metropolitan area, can reduce mortality and length of hospital stay.

OP79 Trends over time in risk of ischaemic stroke and ischaemic heart disease in patients with diabetes mellitus in England **(Article cost: £24)**
OO Seminog, MJ Goldacre - Journal of Epidemiology and Community …, 2014 - jech.bmj.com
There was no decline in the excess risk, when compared to the control population, of ischaemic stroke in patients with DM over the last 13 years. A modest decline was observed in the excess risk of IHD between 1999–2002 and 2003–2006, but this improvement has not continued in recent years. These findings show that diabetes remains an important risk factor for stroke and IHD. They suggest that there were no major improvements in preventing these complications of DM at a population level in England.

PP42 Are we squeezing the pips? Financial austerity and disinvestment in low clinical value procedures in England: a time-trend analysis **(Article cost: £24)**
S Coronini-Cronberg, H Bixby, AA Laverty… - … of Epidemiology and …, 2014 - jech.bmj.com
Our study suggests there is evidence of significant disinvestment in some procedures of low clinical value since the advent of the efficiency savings imposed on the English NHS in 2011/12, including cataract surgery, hysterectomies for heavy menstrual bleeding, and myringotomies. This suggests commissioners could be making efforts to achieve efficiency savings by funding fewer procedures of low clinical value. However, our analysis also

highlights that magnitude of any reductions can vary across deprivation groups, suggesting a need to ensure disinvestment is applied equitably across the population.

A cross-specialty survey to assess the application of risk stratified surgery for differentiated thyroid cancer in the UK **(Article cost: $27.95)**
WL Craig, CR Ramsay, S Fielding… - Annals of The Royal …, 2014 - ingentaconnect.com
There is a substantial contribution to thyroid surgery in the UK by otolaryngology surgeons. Adjusting management according to established case-based risk stratification is not widely applied. Higher caseload was associated with a preference for management tailored to individual risk.

Diagnosis and management of drug allergy in adults, children and young people: summary of NICE guidance **(Article cost: £20)**
K Dworzynski, M Ardern-Jones, S Nasser - BMJ, 2014 - bmj.com
{conclusions not publicly available}

Retrospective database study to assess the economic impact of hip fracture in the United Kingdom **(Article cost: $54)**
D Lambrelli, R Burge… - Journal of medical …, 2014 - informahealthcare.com
Although we did not capture all pre- and postindex costs and healthcare utilisation, this study provides important insights regarding the characteristics of patients with hip fracture, and information that will be useful in burden-of-illness and economic analyses.

A NEW CLINICAL GUIDELINE (2007) AND NATIONAL AWARENESS CAMPAIGN (2011) ACCELERATED BRAIN TUMOUR DIAGNOSIS IN UK CHILDREN... **(Article cost: $38)**
DA Walker, T Chu, A Shah… - Neuro- …, 2014 - neuro-oncology.oxfordjournals.org
{conclusions not publicly available}

The survival of patients with high grade glioma from different ethnic groups in South East England **(Article cost: £33.95)**
T Ratneswaren, RM Jack, D Tataru… - Journal of neuro-oncology, 2014 - Springer
{conclusions not publicly available}

Testicular hypofunction and multiple sclerosis risk: A record−linkage study **(Article cost: price not public)**
J Pakpoor, R Goldacre, K Schmierer… - Annals of …, 2014 - Wiley Online Library
{conclusions not publicly available}

There were 205 articles published in the time period. To read all publicly available scholarly papers that used data, and search by keywords, please see http://www.hscic.gov.uk/whatwelearnt

Knowledge from Commercial Data Use

Commercial providers are not required to have public benefits for their activity, nor do they report use of the data. Therefore, we have no evidence of public benefit.

Where your data went

HHSCIC releases data to eligible organisations that meet defined criteria, for the purposes of the provision of health or adult social care, or for the promotion of health. These organisations and releases are not for the purposes of your direct care, but should generate future knowledge of the types covered in the previous section.

On the 30th September 2014, you enabled the 9Nu4 preference to exclude yourself from future releases of data from the HSCIC. The releases below occurred before that date.

Your data was included in the following releases, for the following reasons. For more details of any release, the work they wish to do, and the past work of that organisation, see the internet links given below:

One Off Releases

Monitor - Casemix HES 2012/13 APC data, grouped using the following National Casemix Office groupers: Payment 14/15, Engagement 15/16 (v1), Reference Costs 10/11 and Reference Costs 11/12. Data is displayed as episode level HRG counts, and additionally split by provider.
To inform the decision making process for determination of the scope and structure of the Engagement 2015/16 Grouper Product.

Monitor - APC 2012/13 Final Year HES data extract (as CSV files), amended as per SUS PbR 2014/15 spelling rules, grouped through Reference Costs 11/12 and Reference Costs 12/13 National Casemix Office Local Grouper(s), both with and without exclusions applied as specified in the Product Description.
To inform decision making with regards to development of the National Tariff

NICOR - Bespoke Extract; HES Inpatient
The aim is to develop further the research potential of audit data to understand better the causes of coronary heart disease, timing and evolution of risk, and the interplay between biological, interventional and environmental factors.

South London and Maudsley Foundation NHS Trust - Bespoke Extract; HES Inpatient, Bespoke Extract; HES Outpatient, HES A&E
To enable the investigation of associations between specific mental disorders seen in secondary mental health care and physical illness.

University of Manchester - Bespoke Extract; HES Inpatient
Sudden Unexplained Death (SUD) in mental health in-patients.

Janssen Healthcare Innovation - Bespoke Extract: HES Inpatient, HES Outpatient, HES A&E, MHMDS & MHMDS-HES Bridging File
Janssen Healthcare Innovation is developing an innovative suite of technology-supported healthcare modules to assist recovery in the areas of mental health, orthopaedic health and cardiac health. For mental health in particular, data will be used to understand impact of mental illness on the health system.

St George's University of London - Bespoke Extract; HES Inpatient, Bespoke Extract; ONS Mortality
We are currently using HES data to investigate the efficiency of the health system for aneurysms. We are also investigating the potential relationship between several endpoints across trusts. We are also interesting in comparing the results found in UK with US.

National Back Office

Your record was included in **3** status checks for repeats of past conditions. Information from it was provided **once** to the 1965 Cohort Study who had lost track of you in 2003 and wished to recontact you to request your continued participation; and was released **once** to the UK Border Agency under a Data Protection Act request.

Ongoing Releases

Public Sector

NHS England - Casemix HES 2012/13 APC data, grouped using the following National Casemix Office groupers: Engagement 15/16 (v1) and Reference Costs 11/12. Casemix HES 2009/10 APC data, grouped using the Reference Costs 11/12 National Casemix Office grouper. Data is displayed at aggregate HRG level

NHS England - HES or SUS - Admitted Patient Care, Emergency Medicine, Non-Admitted Consultations, Adult Critical Care, Neonatal Critical Care and Paediatric Critical Care. Data is released as aggregated counts of episodes at HRG and Dominant Procedure level. Occasionally we may also provide the data at Provider level. We may also provide additional calculated fields e.g. Mean Length of Stay. We do not provide patient level or patient identifiable data.

NHS England - CSUs, CCGs - Data linkage and processing for Invoice Validation
Invoice Validation within CSU/CCG Controlled Environment for Finance

Health Solutions Wales - SUS activity for the current financial year related to patients that are either registered with a Welsh GP or are themselves resident in Wales. Records relate to treatment in English hospitals.

Commissioning - NHS England - CSUs, CCGs - Data linkage and processing for Risk Stratification
Risk Stratification

NHS England - CSUs, CCGs - Data linkage and processing for Accredited Safe Havens
Accredited Safe Haven for commissioning purposes

CSUs, CCGs, NHS England, PHE, LAPH - Data linkage and processing for Commissioning
Commissioning activities of: Validation of provider invoices; Pandemic emergency planning; Monitoring and audit; Provider performance management; Strategic delivery planning; Immunisation monitoring

Commercial Users

Methods Insight Analytics - SHMI data split by trust and diagnosis group
Summary Hospital-level Mortality Indicator (SHMI) data provided quarterly at diagnosis group level for the Acute Trust Dashboard, a freely available resource to the NHS and public featuring metrics on quality from various source in one place. There was a commercial procedural breach by Methods Insight Analytics, which did not reveal any of your individual data. You can find more details of what happened, & how it affects you.

Capita Business Services Ltd - clinical coding audits carried out as part of the 2013/14 PbR Assurance Framework. Data will be used by Capita to support the DH's PbR Data Assurance Framework.

Dr Foster Intelligence - HES/ONS Linked and SHMI derived fields
Commissioned by the Secretary of State for Health for 3rd party support of the Summary Hospital-level Mortality Indicator (SHMI)

CHKS - HES/ONS Linked and SHMI derived fields
Commissioned by the Secretary of State for Health for 3rd party support of the Summary Hospital-level Mortality Indicator (SHMI) Experimental Official Statistics publication. Record-level SHMI data provided quarterly.

Academia

University Hospitals Birmingham - HES/ONS Linked and SHMI derived fields
Commissioned by the Secretary of State for Health for 3rd party support of the Summary Hospital-level Mortality Indicator (SHMI) Experimental Official Statistics. Record-level SHMI data provided quarterly.

Dr Foster Unit at Imperial College London - HES/ONS Linked and SHMI derived fields
Commissioned by the Secretary of State for Health for 3rd party support of the Summary Hospital-level Mortality Indicator (SHMI)

Dr Foster Unit at Imperial College - SUS
Financial year to date plus most recent previous year. All SUS activity records included but a subset of fields.

Concerns

If you haven questions about where your data was accessed for Direct Care purposes, please use the guide on http://www.hscic.gov.uk/whoaccessedyourdata for support in finding answers to your questions.

If you have any other questions about the content of this report, please contact enquiries@hscic.gov.uk

Access to knowledge

From April 2014, all new publicly-funded research is required to be open access, with unrestricted online access to peer-reviewed scholarly research. Research funded earlier, or outside the UK, may require payment of an additional fee per reader. If you would support HSCIC mandating that all publications using public data be open access, please email a statement of support to enquiries@hscic.gov.uk

If you have opted out of your data being included in data releases, we will continue to show you research resulting from releases prior to your objection being implemented.

HSCIC's consideration of this document is being led by Max Jones.

For where you will be seeing this next, please contact
coordinator@medconfidential.org