

NHS England

Introducing care.data

A modern data service for the NHS




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Chief Data Officer

THE NHS CONSTITUTION
The NHS belongs to us all

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NHS England is commissioning care.data on behalf of the ISCG

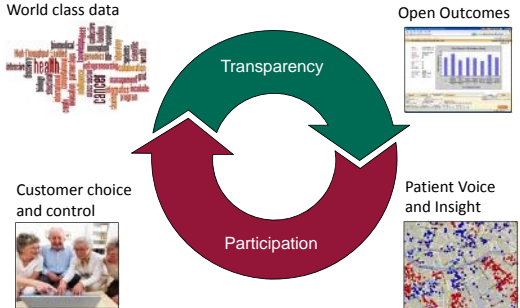
ISCG Informatics Services Commissioning Group



The role of the ISCG is to commission services within an agreed strategic framework and then to monitor their delivery against set objectives

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Virtuous circle leading to high quality care for all



World class data

Open Outcomes

Transparency

Customer choice and control

Participation

Patient Voice and Insight

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Upgrading HES

Our starting point for world class data: HES

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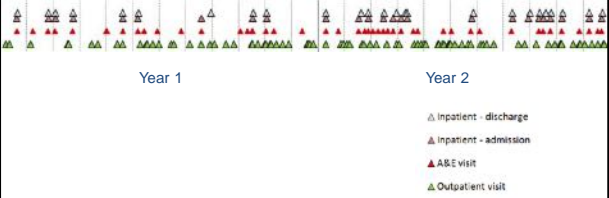
- Hospital Episode Statistics (HES) is a world-class data service containing details of all NHS hospital activity in England
- Primary purpose is health care analysis for the NHS and the Department of Health
- Records every **inpatient** 'episode' (1989 onwards), **outpatient** attendance (2003 onwards) and **A&E** attendance (2007 onwards)
- Invaluable research tool – tens of thousands of peer-reviewed articles and audits



Dame Edith Körner (1921-2000)

Two years of HES data for one individual patient

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Year 1 | Year 2


- △ Inpatient - discharge
- ▲ Inpatient - admission
- ▲ A&E visit
- ▲ Outpatient visit

HES contains records for the whole population dating as far back as 1989

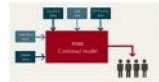
Uses of HES

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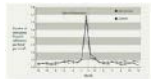
Describing: to describe patterns of hospital activity over time




Predicting: to build predictive models that determine risk of adverse events



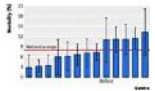
Evaluating: Modern methods, such as *propensity score matching*, use HES data to create synthetic controls



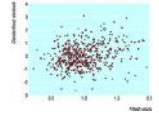
Comparing: to compare health needs and use of services in different areas.



Auditing: to help assess the quality of hospital care.




Investigating: to detect associations.



Problems with HES

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- Variable data quality and completeness**
- Very difficult for patients to access** their own data
- Missing data:**
 - No information about in-hospital prescribing, investigations, observations, etc.
 - No information about care outside hospital
 - No information about social care



Questions that cannot be answered using HES

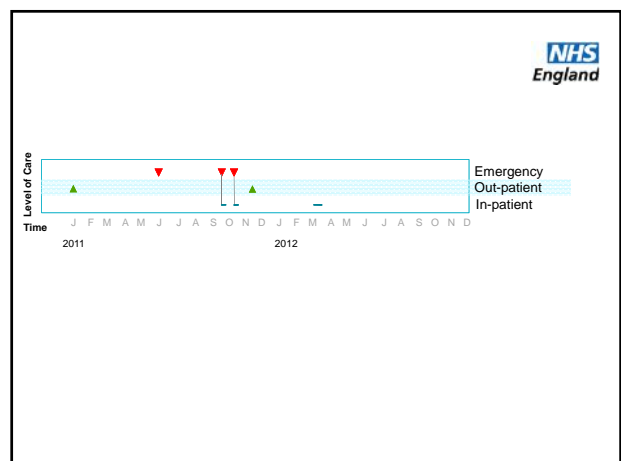
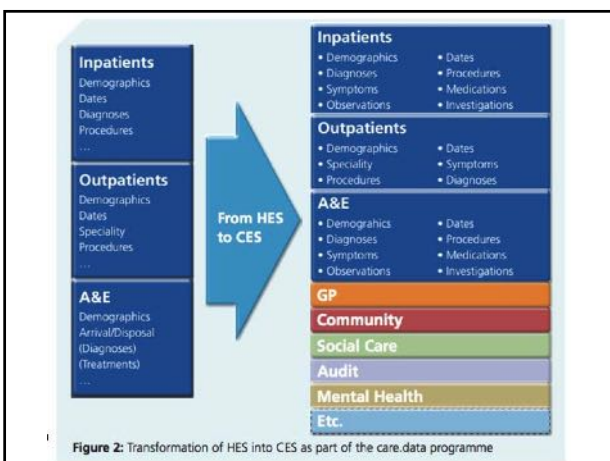
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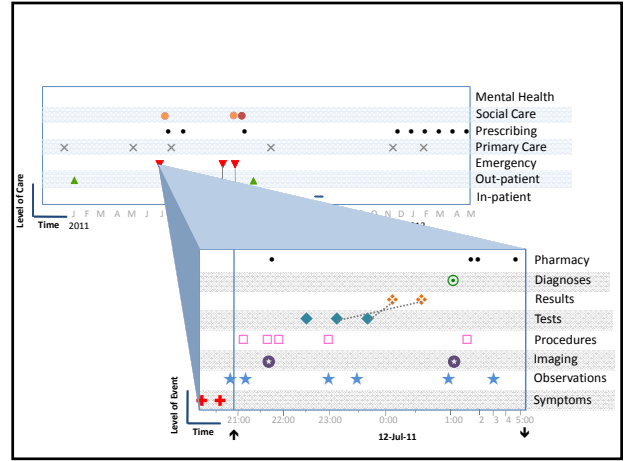
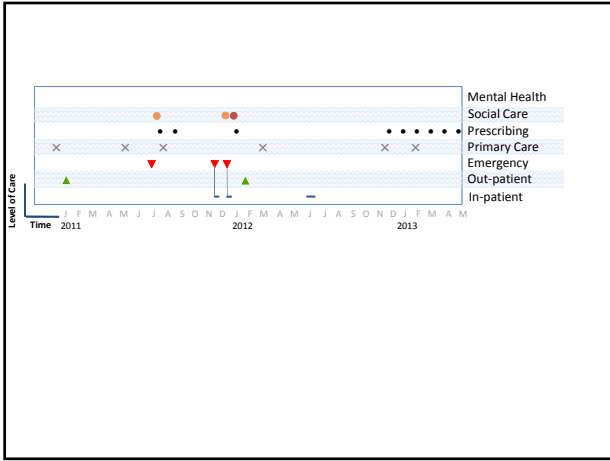
- How many patients in England received chemotherapy last year?
- What proportion of patients in St. Mary's hospital were reviewed by a consultant at least once a day?
- For patients in Birmingham versus Bristol, what was the average time between presenting to their GP with bowel symptoms to being diagnosed with colon cancer?
- What proportion of patients on Ward 20 who had highly abnormal nursing observations were reviewed by the intensive care outreach team within an hour?



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From HES to CES





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Information Governance

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Protecting privacy

A diagram showing five interconnected teal hexagons representing legal frameworks for privacy protection: NHS Constitution, Human Rights Act, Data Protection Act, 2nd Caldicott Review, and Health & Social Care Act.


Three types of data



- Identifiable data** → Contains identifiers such as date of birth and postcode
- Potentially identifiable data** → Contains a unique pseudonym for each person
- Non-identifiable data** → Contains aggregated or anonymous data


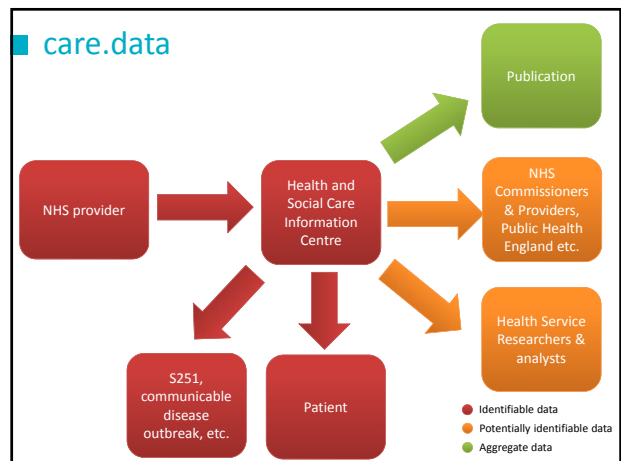
Each type of data is protected by a different suite of privacy safeguards

Safeguards




- Identifiable data**
Extracted into the secure environment of the **HSCIC**
Disclosed by the HSCIC only where there is a legal basis (e.g. section 251 approval) or with patient consent.
- Potentially identifiable data**
Available only to approved organisations for approved purposes under a **legal contract**
Wide **range of safeguards** as specified by the information commissioner's office (e.g., purpose limitation, prohibition of re-identification, time limits for destroying data, contractual penalties)
- Non-identifiable data**
Published **openly**
Safeguards to ensure that the data are truly anonymous in line with ICO advice (e.g., **small-number suppression**, perturbation, rounding)

Data Flows





Inbound data




- Using its powers under the Health and Social Care Act 2012, NHS England is **directing** the HSCIC to collect primary care data and link them to HES data.
- The GP data set was reviewed by an expert subcommittee of the **Joint GP IT Committee** of the British Medical Association and the Royal College of General Practitioners
- It was subsequently approved by the **independent advisory group** (IAG) of the GP Extraction Service (GPES)

Inbound data




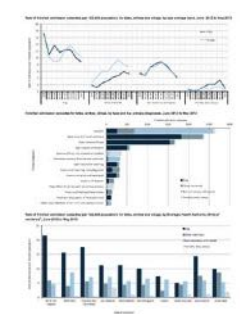
- The GP data extract will contain the following identifiers
 - NHS number
 - Date of birth
 - Gender
 - Postcode
- The HSCIC needs these four identifiers in order to **link the data accurately**
- No names or addresses** will be extracted
- No free text** will be extracted

Data processing and linkage




- Data linkage occurs within the **secure environment** of the HSCIC
- Automated process** with occasional checking by HSCIC analysts
- Wide range of safeguards in place to protect confidentiality, including:
 - Patient identifiers held separately from clinical coded information
 - Protection against attacks from unauthorised individuals
 - Safeguards against careless or negligent behaviour by staff
 - Access to the data by HSCIC personnel is restricted
 - Wherever practicable, such staff are assigned rights either to patient identifiers or to clinical data **but not both**

Open data





- Aggregated or anonymous data
- Safeguards to ensure that the data are truly anonymous (e.g., small number suppression)
- Published openly
- Aiming for 5* standard of openness
 - Published under an open licence
 - Structured data
 - Non-proprietary formats (e.g. CSV)
 - URLs published
 - Linked to other data to provide context

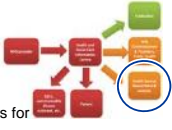
Data for commissioners



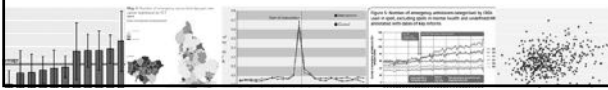
- Pseudonymous data
- Available to commissioners (i.e., NHS England, clinical commissioning groups, and local authorities)
- Used for assessing a population's health needs, planning services, and monitoring services in terms of
 - Quality
 - Efficiency
 - Equity




Data for approved analysts




- Pseudonymous data
- Available under a **legal contract** to accredited organisations for approved projects only
- Wide **range of safeguards** in place including purpose limitation, prohibition of re-identification, contractual penalties, etc.
- Ambition is to reduce costs of accessing the data to a minimum.
- We want to encourage charities, small academic units, SMEs etc. to use the data
- No dilution of the robust information governance safeguards currently used by HES




My data



- Personal confidential data
- Patients already have the right to obtain their HES data but there are no systems in place yet to allow patients to download or view their own data
- Patients will be able to:
 - Share their data with their **family or carers**
 - Share their data with their treating clinician
 - Send their data to a trusted third party for analysis (e.g., Diabetes UK)
 - Use their data to find patients in a similar to situation to themselves
- Analogous to the **Blue Button+** offered by the U.S. Centers for Medicare & Medicaid Services



Legally mandated data flows



- Personal confidential data
- Only disclosed where there is a legal basis (e.g., Section 251 approval) or with patient consent.
- Examples are:
 - Section 251 of the NHS Act (use of data for research that would not otherwise be possible) if approved by the Confidentiality Advisory Group
 - Public Health legislation (to prevent the spread of infectious diseases)
 - Court order
 - Overriding public interest in disclosure (e.g., serious imminent threat to public health or national security)

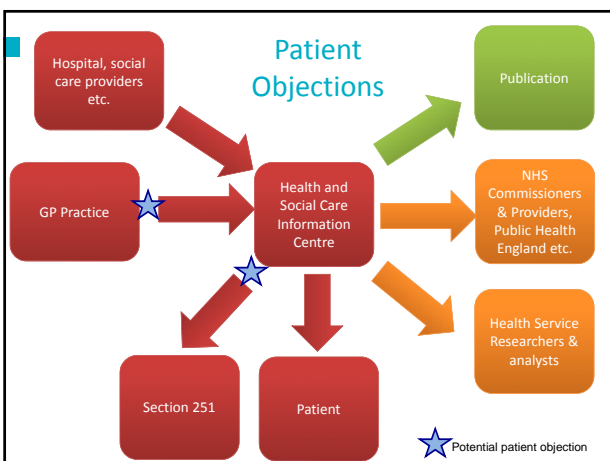
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Patient Objections

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Patient objections

- The Health and Social Care Act 2012 **overrides the common law** duty of confidentiality requirement to seek patient consent
- NHS England and the HSCIC **value patient confidentiality** and recognise that some patients may have concerns.
- The Secretary of State announced that patients should be able to object to confidential data flows from GP practices to the HSCIC.
- NHS England and the HSCIC will **honour such objections**
- Patients can object to the disclosure of their personal confidential data
 - By their GP practice
 - By the HSCIC



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Awareness Raising

Fair Processing



- As data controllers, GPs have a **duty to inform their patients** about how their confidential data will be processed and shared
- This duty is known as **fair processing**
- NHS England has been working closely with the BMA and the RCGP to develop materials to support GPs with these duties
- In addition, NHS England is undertaking a wide range of activities at a **regional** and **national** level to raise awareness among patients, with a further announcement due shortly



Patient Materials



- Include posters, leaflets, and FAQs developed jointly by NHS England, the HSCIC, the BMA and the RCGP
- These materials were
 - reviewed by the BMA's **patient liaison group**
 - piloted** in a small number of practices
 - then **revised** based on the feedback received



Local Awareness Raising



- As data controllers, GP practices need to engage proactively with their patients, for example by:
 - providing information at **reception**
 - including information on **repeat prescriptions**
 - placing information on the **practice website** and online appointment booking page
 - using GP practice communication channels (e.g. **newsletters**)
 - using **patient participation groups** to communicate messages

National Awareness Raising



- NHS England and the HSCIC are supporting practices to raise awareness, for example through
 - Online and social media campaigns, (for example, there are dedicated patient support pages on the NHS Choices website, together with an article on the front webpage, which receives over 20 million hits a month)
 - Articles in national media
 - Sending information to tens of thousands of charities and voluntary groups, who have been asked to cascade the information to their members
- Further announcement due shortly



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Benefits

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Purpose: to supply timely, accurate information to citizens, clinicians and commissioners about NHS care (i.e., a modern data service)

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<p>Current position: Local initiatives and national registers operate largely in isolation</p>	<p>Potential benefits from prescribing in care homes and home monitoring. Some leading hospital sites capture detailed data</p>	<p>Patients with LTCs in active participation. Leading hospital sites' prescribing results. Work with social care data pioneers.</p>	<p>Patients with access e.g. to path results.</p>
<p>Current</p>	<p>Phase 1</p> <ul style="list-style-type: none"> Mental health data GP data 	<p>Phase 2 (TBC)</p> <ul style="list-style-type: none"> Detailed hospital data Clinical audit data Disease registry data 	<p>Phase 3 (TBC)</p> <ul style="list-style-type: none"> Community health services data Social care data
<p>2012/13</p>	<p>2013/14</p>	<p>2014/15</p>	<p>2015/16</p>