

Collecting Information in the NHS

*Bracknell and Ascot Clinical Commissioning Group
Slough Clinical Commissioning Group
Windsor, Ascot and Maidenhead Clinical Commissioning Group*

Types of information

- **identifiable** - containing details that identify individuals
- **pseudonymised** - about individuals but with identifying details (such as name or NHS number) replaced with a unique code
- **anonymised** - about individuals but with identifying details removed
- **aggregated** - anonymised information grouped together so that it doesn't identify individuals

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Legal responsibilities

We have different legal responsibilities for different types of information we collect.

We must:

- Publish **anonymised information** so that it's freely available to everyone
- Follow the rules for **identifiable information** as set out in the *Data Protection Act 1998* and the *Common Law Duty of Confidence*

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Collections

NHS England collects information from health and care organisations. They use some of the information collected to produce:

- statistical reports
- open data
- indicators
- audits
- fast facts for journalists

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Example Collections

- Hospital Episode Statistics (HES) - care and treatment of people in hospital
- Mental Health Minimum Data Set (MHMDS) - care of adults and older people using secondary mental health services
- Patient Reported Outcome Measures (PROMs) - questionnaires for hip replacement, knee replacement, varicose vein and groin hernia
- Diagnostic Imaging Data Set - diagnostic imaging tests, such as x-rays and MRI scans, including waiting times.

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Planned Collections

Care.data programme - diagnosis, treatment and care at general practices

The care.data programme will be phased in with a selection of GP practices from autumn 2015. This is to ensure the collection is thoroughly trialled and to demonstrate it is safe before a national roll-out. This has been agreed with patient groups, The British Medical Association, Healthwatch, Royal College of General Practitioners, and the care.data advisory group.

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Care.data programme

The programme will start by collecting information about the care provided in GP practices and join up this information with information collected from hospitals.

Those who plan and monitor services in the NHS are currently missing information about the care provided outside hospital, in GP and community settings, and after patients return home. This is a problem, as no-one really knows how well all the different parts of the system are working together.

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What will be collected?

Where a referral, prescription, diagnosis, or other health related event has taken place in the last 4 months, it will be collected each month from General Practice electronic patient records. The information will be coded (for example code C10EL for diabetes). Information collected:

- NHS number
- Date of birth
- Gender
- Postcode
- Ethnicity

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What will NOT be collected?

Data relating to sensitive information including HIV/AIDS, sexually transmitted infections, termination of pregnancy, IVF treatment, marital status, complaints, convictions, imprisonment, and abuse by others.

NHS England will not collect information that GPs record as written notes, such as details of any conversations that they have had with the patient.

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What happens to the data?

Information about the care provided in GP practices will be joined up with information collected from hospitals to give a more rounded picture of what is happening in our health and care services across the country.

The NHS will have a more complete picture of the care being delivered, know where money needs to be invested in treating diseases and conditions, and quickly understand where there might be local problems that need to be fixed.

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