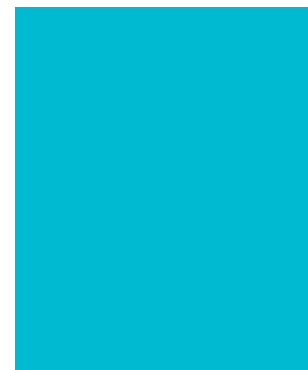
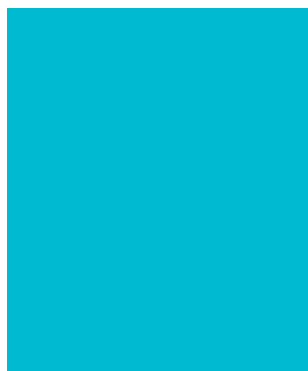


# care.data: listening to you



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# Care.data is

- ...branded as '**Better information means better care**'
- A secondary or indirect care database – not a real time database to share data for immediate/direct care uses in surgery or at bedside.
- NOT the same as the Summary Care Record
- Intends to be a set of linked data from all NHS and social care settings to enable better commissioning, research, public health, clinical audit and performance and system management

# The current position

- Care.data builds on existing hospital data – HES – adding new data
- It is acknowledged that NHS England needs to do more to explain the programme to professionals and the public
- Some parts of the programme are being reviewed
- Extraction of data halted until at least the autumn 2014
- NHS England will spend this time gaining views from and communicating more clearly about the programme, with patients, the public and the NHS

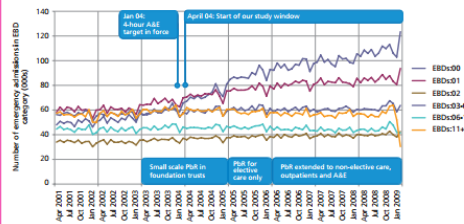
# The benefits of the programme

- Research into the effectiveness of treatment and how effective services are, through:
- A much more detailed data set which is capable of answering multiple queries and information needs
- Improving the quality of services and outcomes through determining better treatment
- Identification of links between prescribing etc and effects – such big data proven to prevent a future thalidomide, identify faulty devices etc

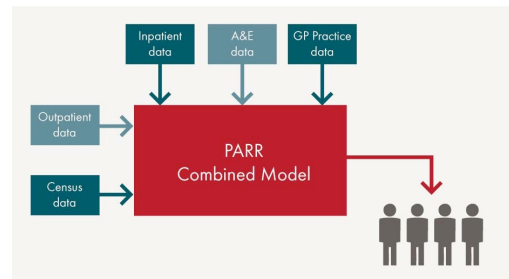
# ■ Uses of HES

**Describing:** to describe patterns of hospital activity over time

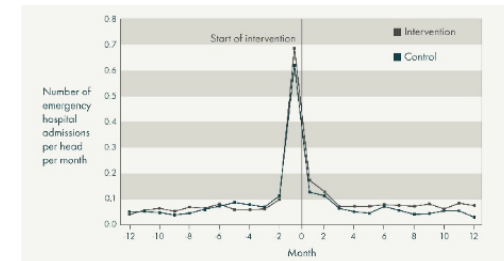
Figure 5: Number of emergency admissions categorised by EBDs used in spell, excluding spells in mental health and undefined HRGs, annotated with dates of key reforms



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



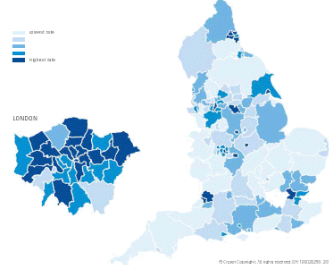
**Evaluating:** Modern methods, such as *propensity score matching*, use HES data to create synthetic controls



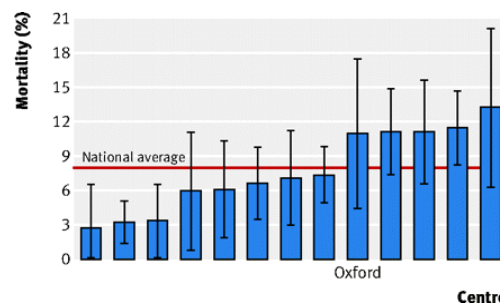
**Comparing:** to compare health needs and use of services in different areas.

Map 3: Number of emergency cancer bed-days per new cancer registration by PCT 2009/10

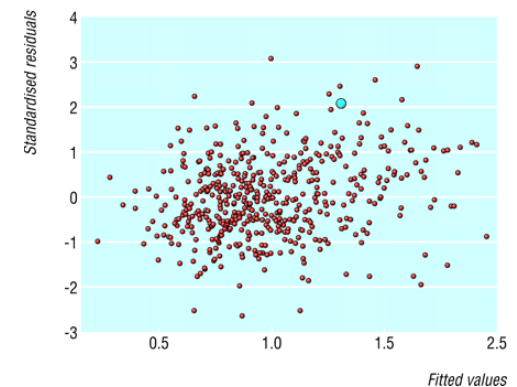
Details: 1. Showing people from dying prematurely



**Auditing:** to help assess the quality of hospital care.



**Investigating:** to detect associations.



**Inpatients**  
 Demographics  
 Dates  
 Diagnoses  
 Procedures  
 ...

**Outpatients**  
 Demographics  
 Dates  
 Speciality  
 Procedures  
 ...

**A&E**  
 Demographics  
 Arrival/Disposal  
 (Diagnoses)  
 (Treatments)  
 ...



**Inpatients**

- Demographics
- Diagnoses
- Symptoms
- Observations
- Dates
- Procedures
- Medications
- Investigations

**Outpatients**

- Demographics
- Speciality
- Procedures
- Dates
- Symptoms
- Diagnoses

**A&E**

- Demographics
- Diagnoses
- Symptoms
- Observations
- Dates
- Procedures
- Medications
- Investigations

**GP**

**Community**

**Social Care**

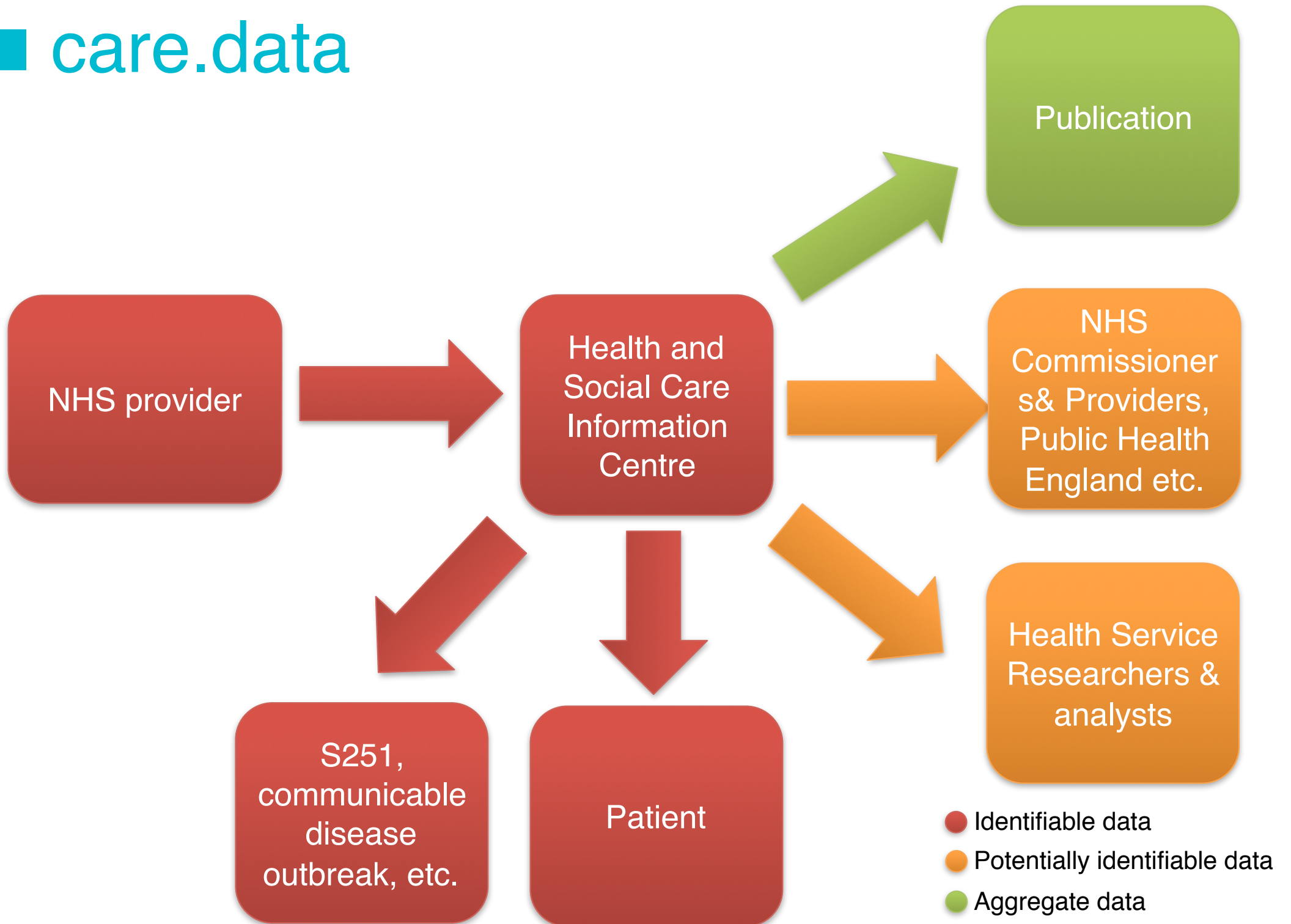
**Audit**

**Mental Health**

**Etc.**

**Figure 2:** Transformation of HES into CES as part of the care.data programme

# ■ care.data



# GP Data to be Collected (as of 29-4-14)

- The information to be extracted from GP systems by the HSCIC includes:
  - family history, vaccinations, diagnoses, referrals, measurements (such as blood pressure), test results (such as cholesterol), and prescriptions.
- This information will only be collected as a **series of codes** (e.g., code X40J5 for diabetes).
- We will not be collecting any “notes” or “free text” (i.e., no information in the form of words or sentences will be collected).
- Sensitive conditions are omitted



# Changes already announced

- Controls on the sale of data to non-healthcare purposes
- Audit and release of information on previous data releases
- An enhanced and legally constituted group to approve any release
- Fines/bans for re-identifying data
- A new independent advisory group
- A new attempt at raising awareness
- Phased roll-out

# The controversial issues: lets hear your views

- Your rights to opt-out and why we use opt-out, not opt-in
- What does pseudonymised data actually mean, and why can't data be anonymised?
- The supply or sale of patient data to non-NHS interests
- The security of the data
- How we communicate the programme to the public
- Why do we need data that is so identifiable?