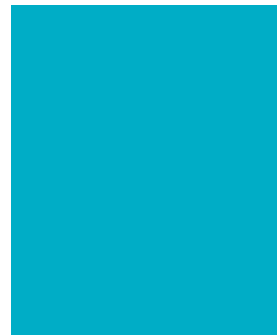
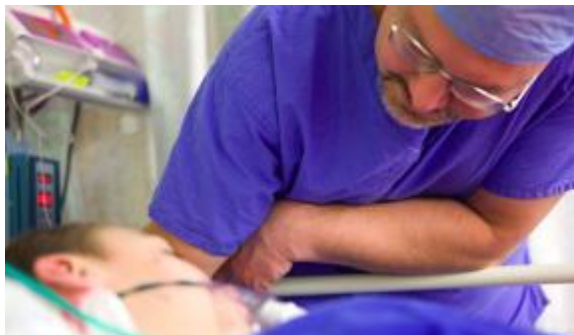
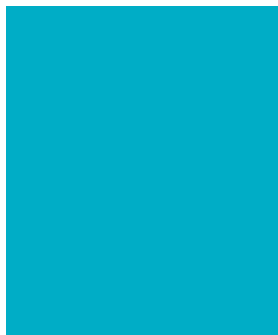


# Introducing care.data

*A modern data service for the NHS*



Dr. Peter Flynn  
Head of Strategic Intelligence  
Programme Director – care.data



# ■ Agenda

- Context/Why? & Aims of the programme
- Current position and its limitations
- Building from that base
- Information Governance and Safeguards
- Data Flows & High level Plan
  - GP data
- Use of the data
- Awareness raising

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



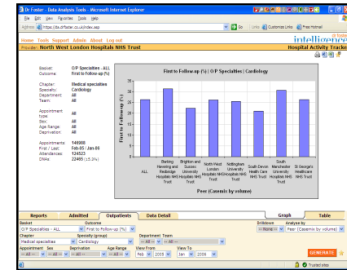
*The role of the ISCG is to commission services within an agreed strategic framework and then to monitor their delivery against set objectives*

# Virtuous circle leading to high quality care for all

World class data



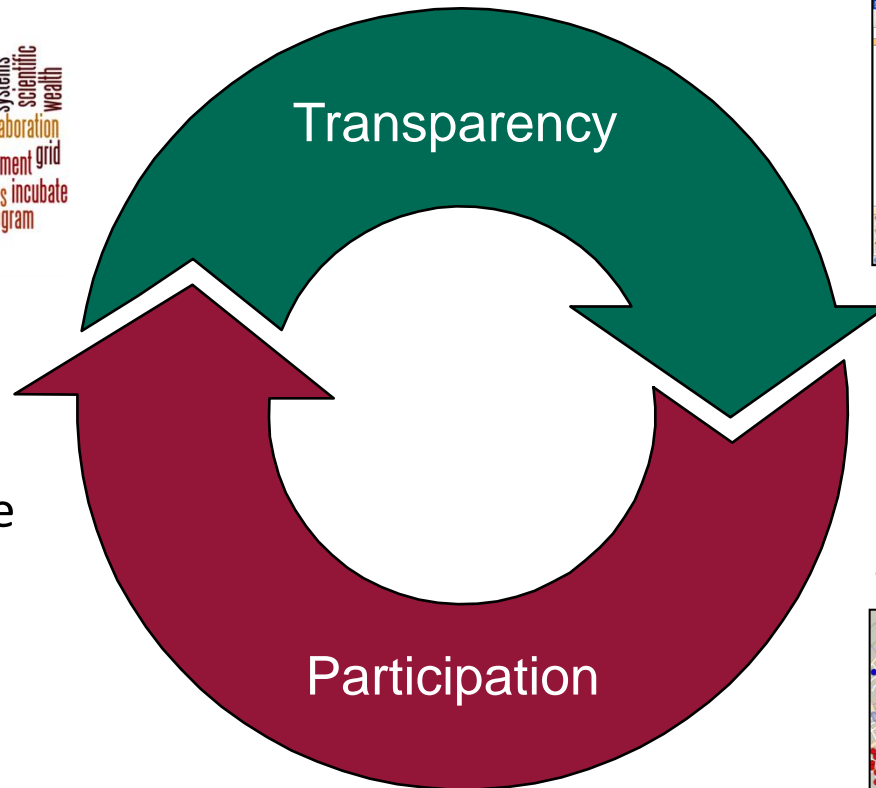
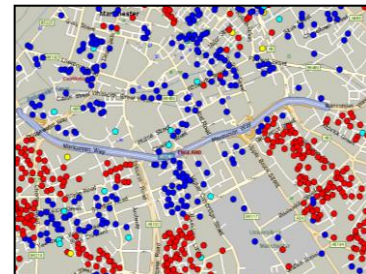
Open Outcomes



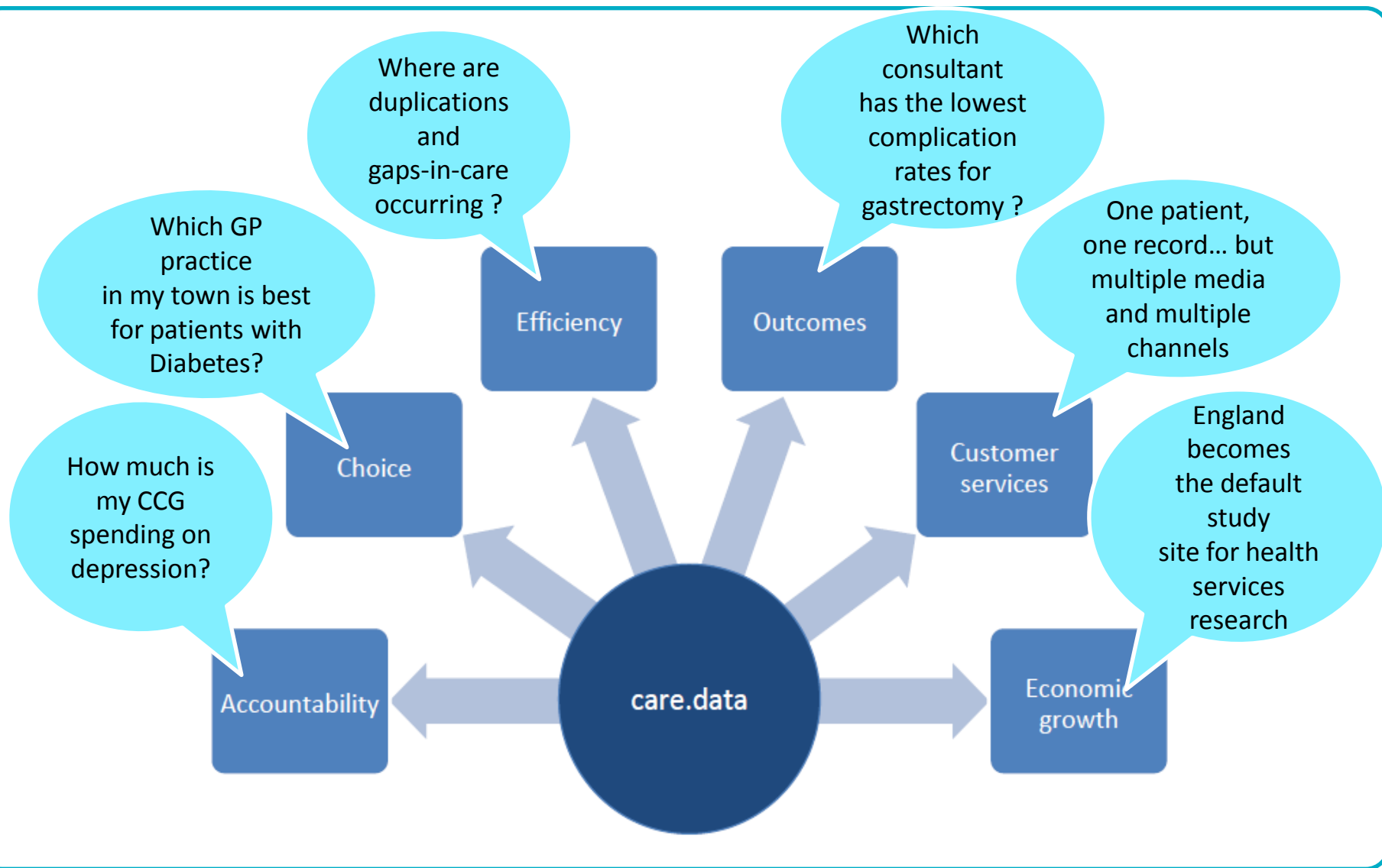
Customer choice and control



Patient Voice and Insight



# Programme Aims



# Our starting point for world class data: HES

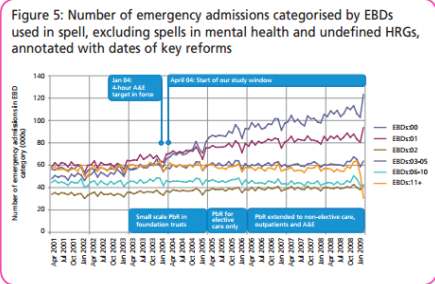
- Hospital Episode Statistics (HES) is a world-class data service containing details of all NHS hospital activity in England
- Primary purpose is health care analysis for the NHS and the Department of Health
- Records every **inpatient** 'episode' (1989 onwards), **outpatient** attendance (2003 onwards) and **A&E** attendance (2007 onwards)
- Invaluable research tool – tens of thousands of peer-reviewed articles and audits
- August 2012-July 2013
  - 18.5m inpatient episodes
  - 95m Outpatient attendances
  - 18.3m A&E attendances



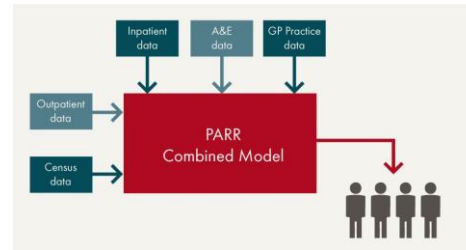
Dame Edith Körner (1921-2000)

# Uses of HES

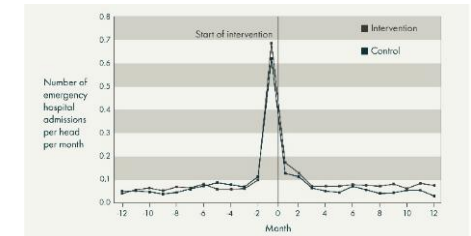
**Describing:** to describe patterns of hospital activity over time



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

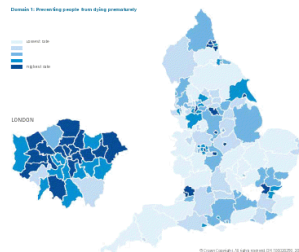


**Evaluating:** Modern methods, such as *propensity score matching*, use HES data to create synthetic controls

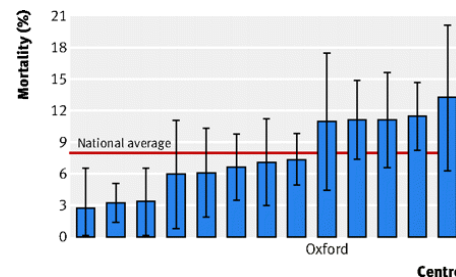


**Comparing:** to compare health needs and use of services in different areas.

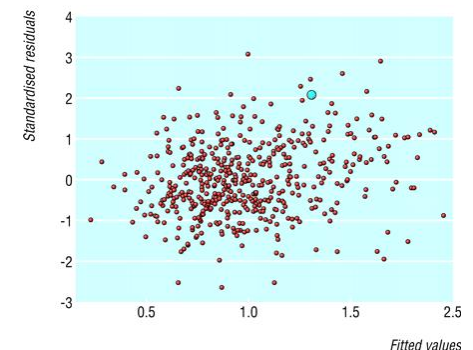
Map 3: Number of emergency cancer bed-days per new cancer registration by PCT 2009/10



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



**Investigating:** to detect associations.

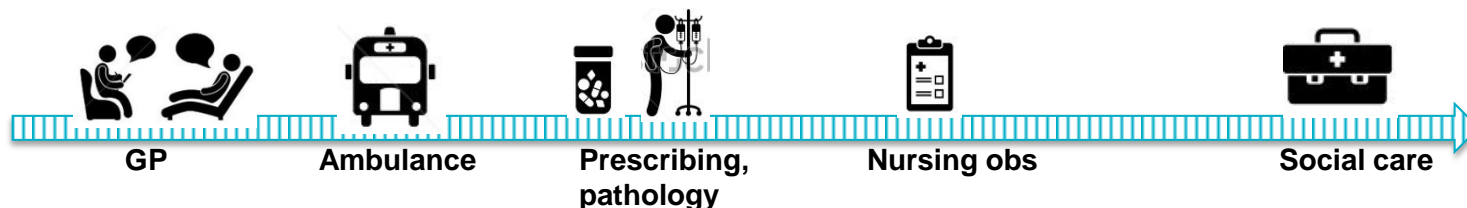


# ■ Limitations of HES

Now:



Future :

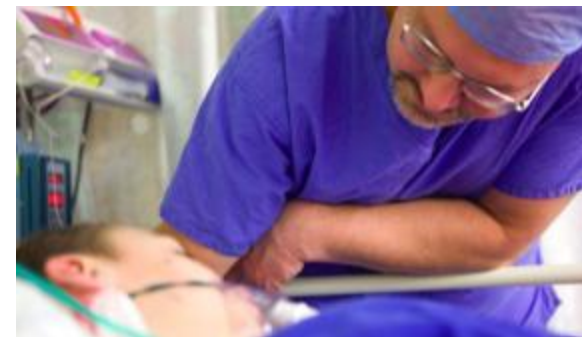


- HES does not currently include data for many important aspects of care e.g. prescribing, nursing observations, tests
- The full patient journey does not exist at national level. HES alone can not be used to investigate many scenarios e.g. time from initial diagnosis (usually at a GP) to treatment.
- Very difficult for patients to access their own data
- No information about care outside hospital
- No information about social care

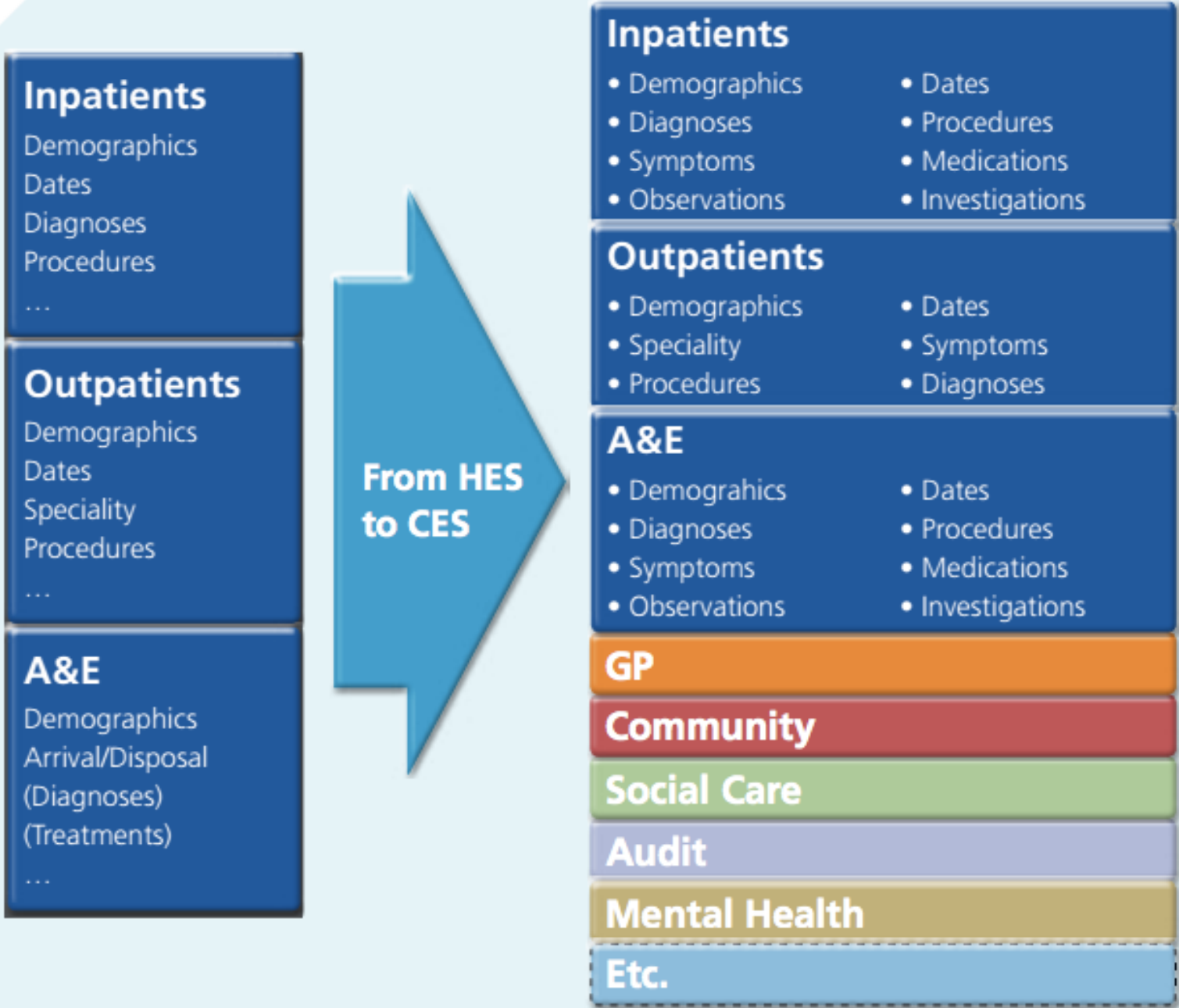


# Questions that cannot be answered using HES

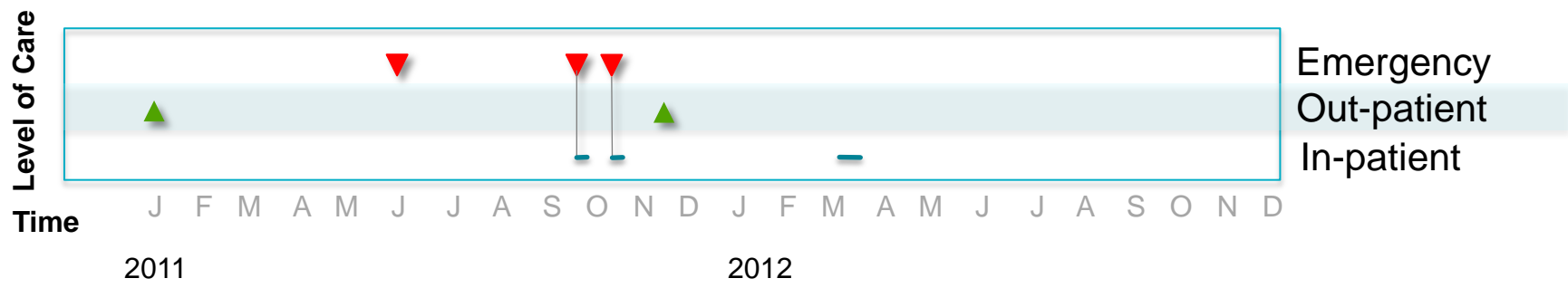
- How many patients in England received chemotherapy last year?
- What proportion of patients in St. Mary's hospital were reviewed by a consultant at least once a day?
- For patients in Birmingham versus Bristol, what was the average time between presenting to their GP with bowel symptoms to being diagnosed 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?

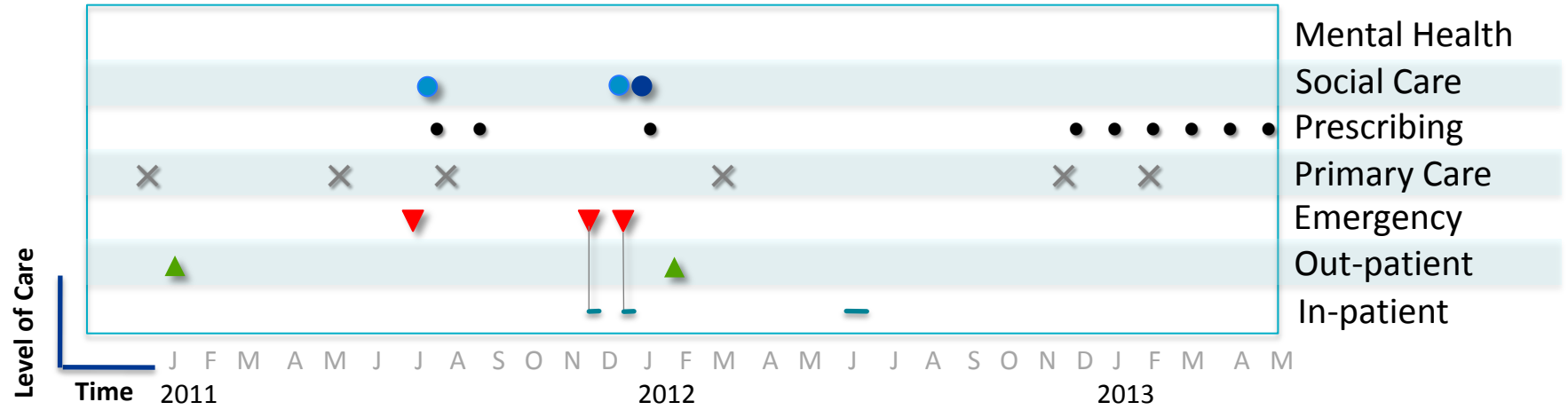


# Building from that base



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

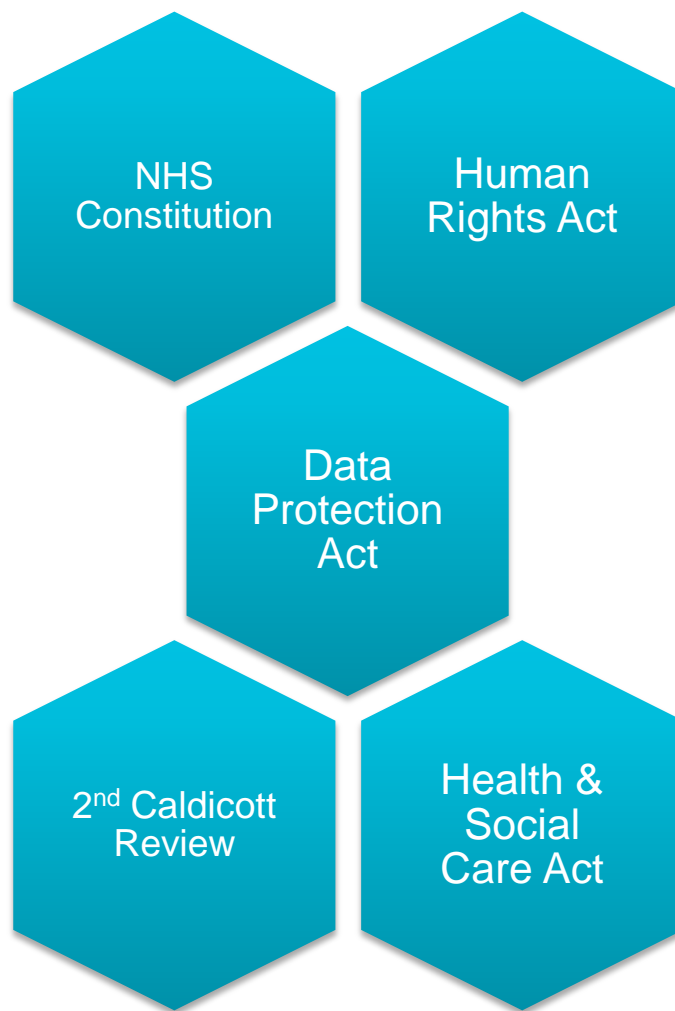




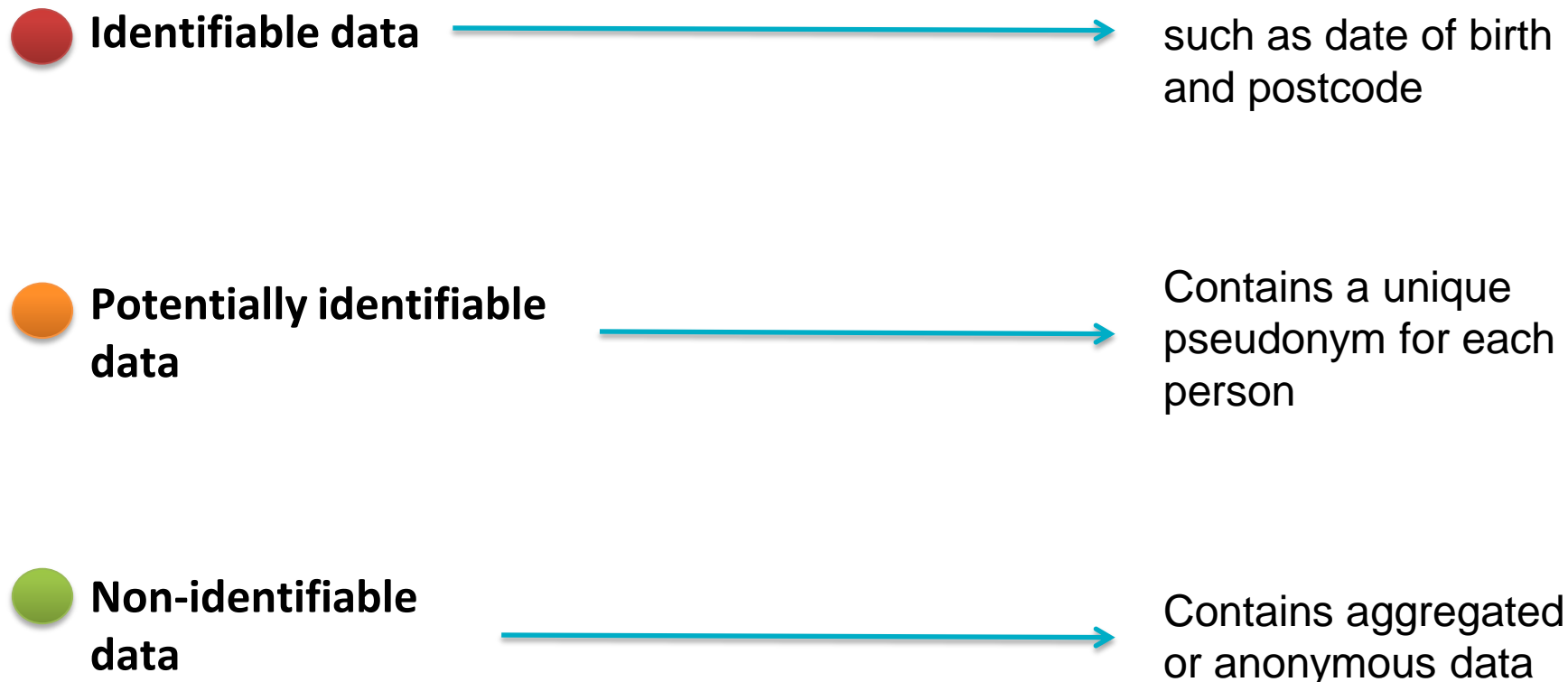
# Information Governance and Safeguards

# Information Governance

## Protecting privacy



# Three types of 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)

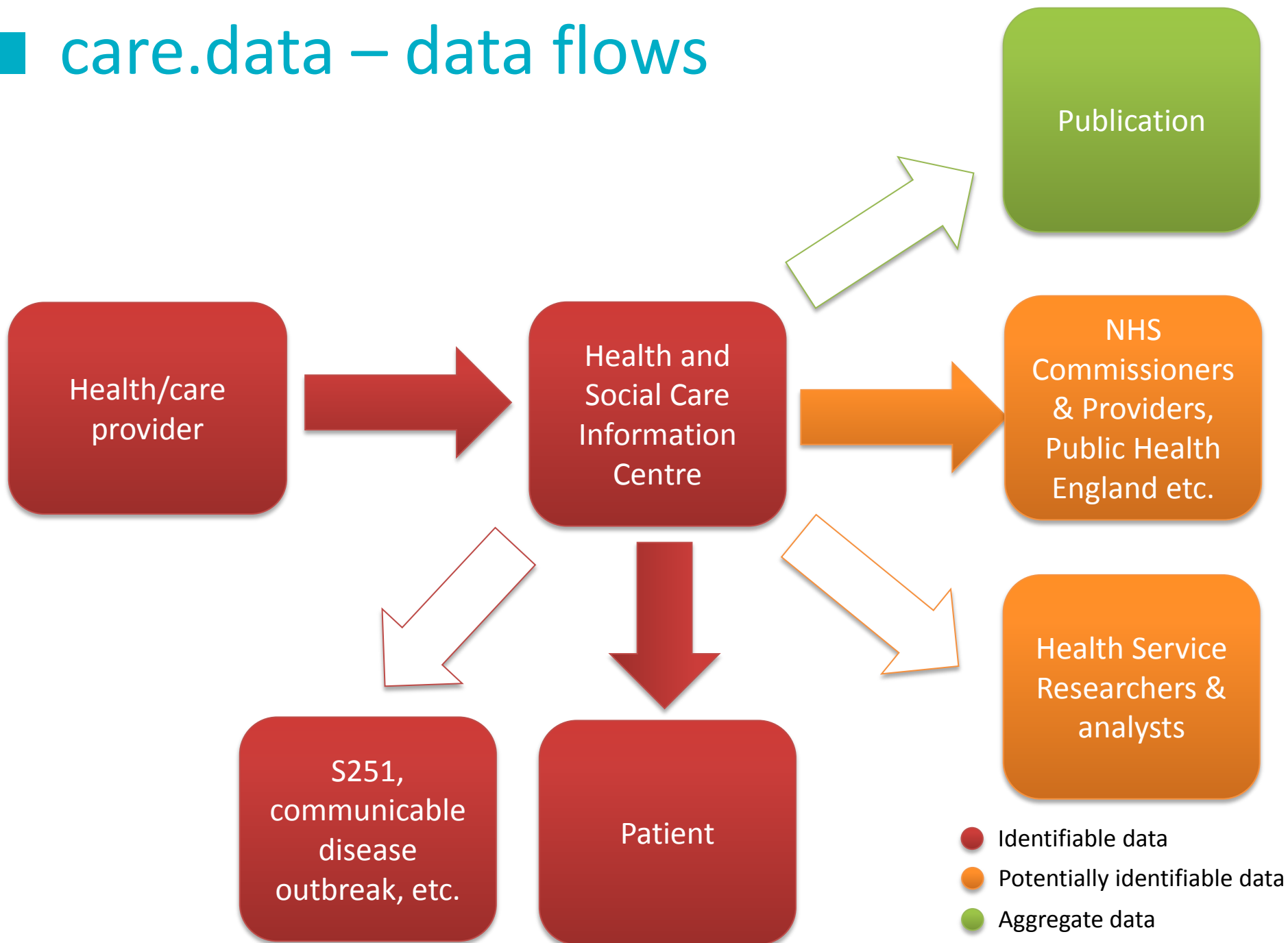
## Non-identifiable data

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 & High Level Plan

# care.data – data flows



# High level Plan

**Current position:**  
Local initiatives and national registers operate largely in isolation

**Current**

- HES

Potential benefits from prescribing in care homes and home monitoring.  
Some leading hospital sites capture detailed data

**Phase 1**

- Mental health data
- Diagnostic Imaging data
- GP data

Patients with LTCs in active participation.  
Leading hospital sites' prescribing results.  
Work with social care data pioneers.

**Phase 2 (TBC)**

- Detailed hospital data
- Clinical audit data
- Disease registry data

Patients with access e.g. to path results.

**Phase 3 (TBC)**

- Community health services data
- Social care data

2012/13

2013/14

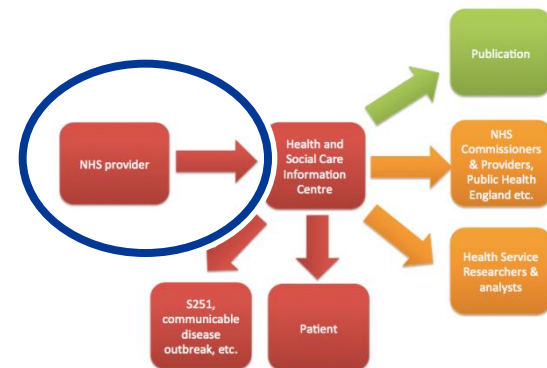
2014/15

2015/16



# Inbound data

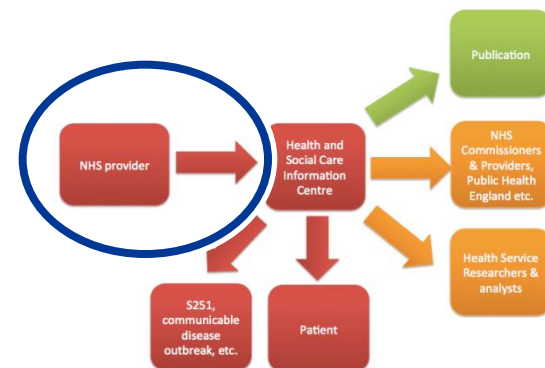
## GP Data



- 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)

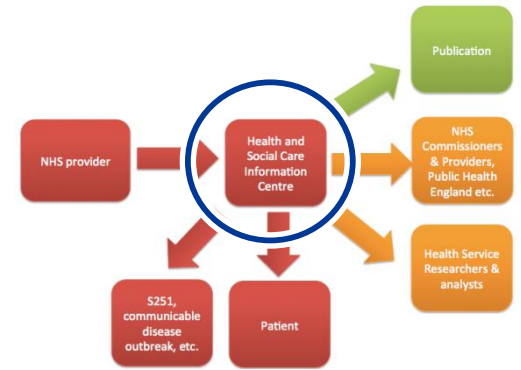
# Inbound data

## GP 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

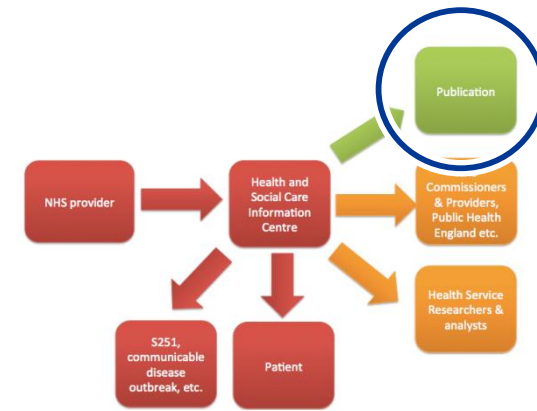


- Data linkage occurs within the **secure environment** of the HSCIC
- **Automated process** with occasional checking by HSCIC analysts
- Wide range of safeguards in place to protect confidentiality, including:
  - Patient identifiers held separately from clinical coded information
  - Protection against 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**

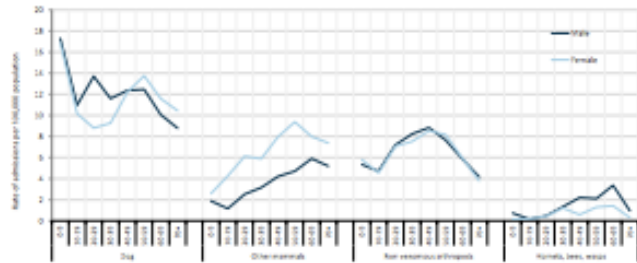
# Use of the Data



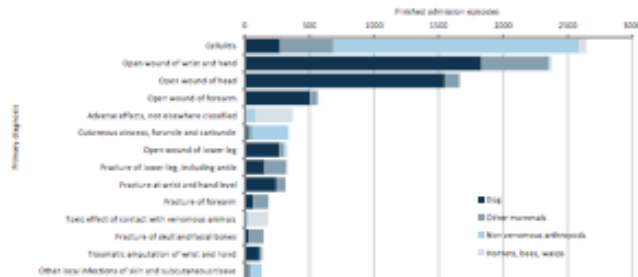
# Open data



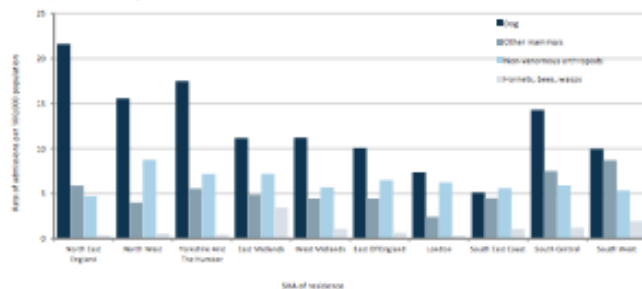
Rate of finished admission episodes (per 100,000 population) for bites, strikes and stings, by type and age band, June 2012 to May 2013



Finished admission episodes for bites, strikes, stings, by type and top primary diagnoses, June 2012 to May 2013

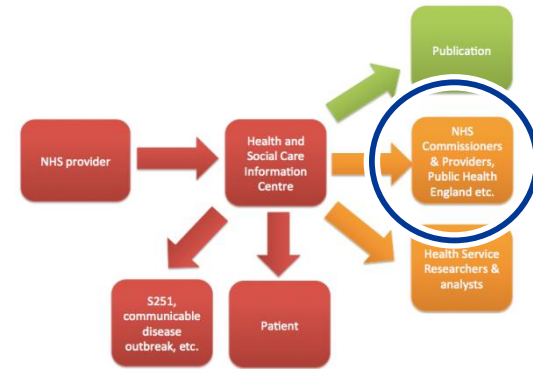


Rate of finished admission episodes (per 100,000 population) for bites, strikes and stings, by Strategic Health Authority (SHA) of residence\*, June 2012 to May 2013



- 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

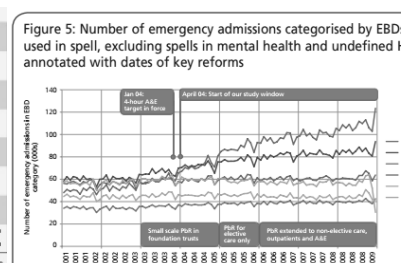
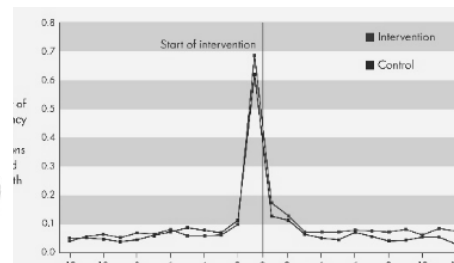
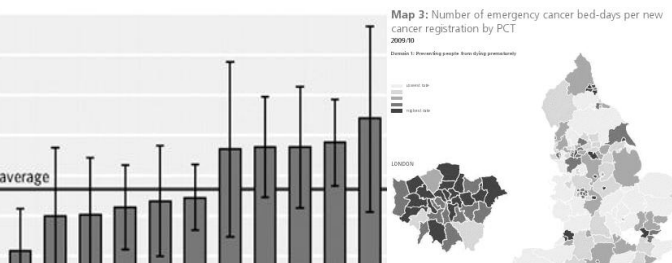
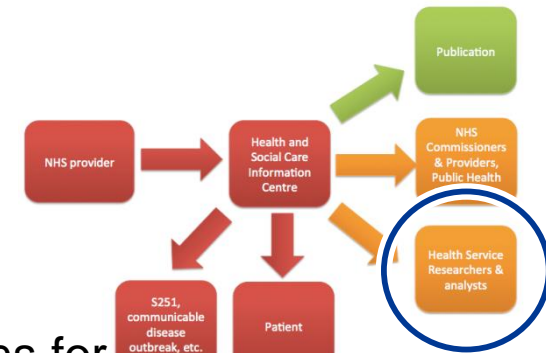


- Pseudonymous data
- Available to commissioners (i.e., NHS England, clinical commissioning groups, and local authorities)
- Used for assessing a population's health needs, planning services, and monitoring services in terms of
  - Quality
  - Efficiency
  - Equity

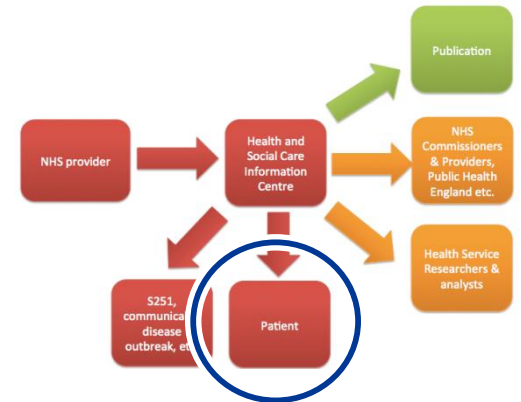


# Data for approved analysts

- 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



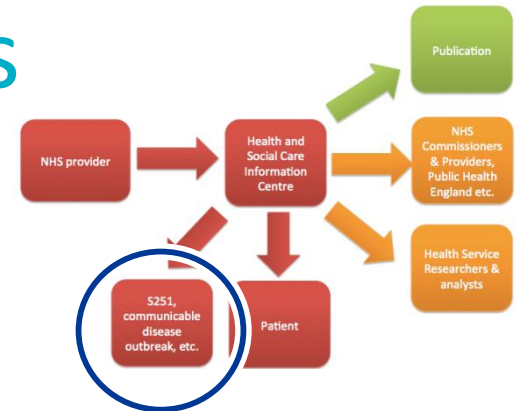
# My data



- 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)

# ■ 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

# Patient Objections

Hospital, social care providers etc.

Publication

GP Practice


Health and Social Care Information Centre

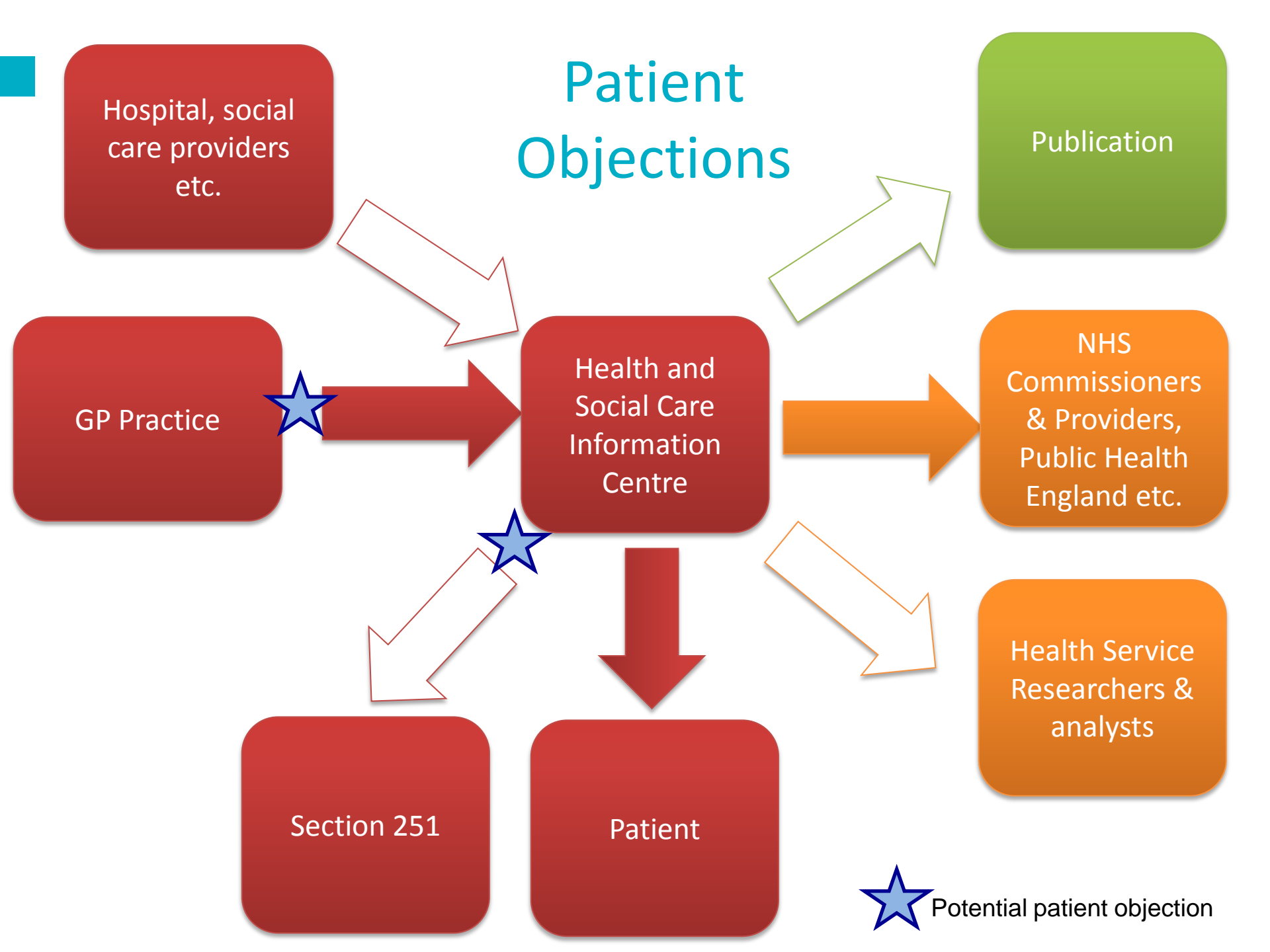
NHS Commissioners & Providers, Public Health England etc.

Section 251

Patient

Health Service Researchers & analysts

 Potential patient objection



# Awareness Raising



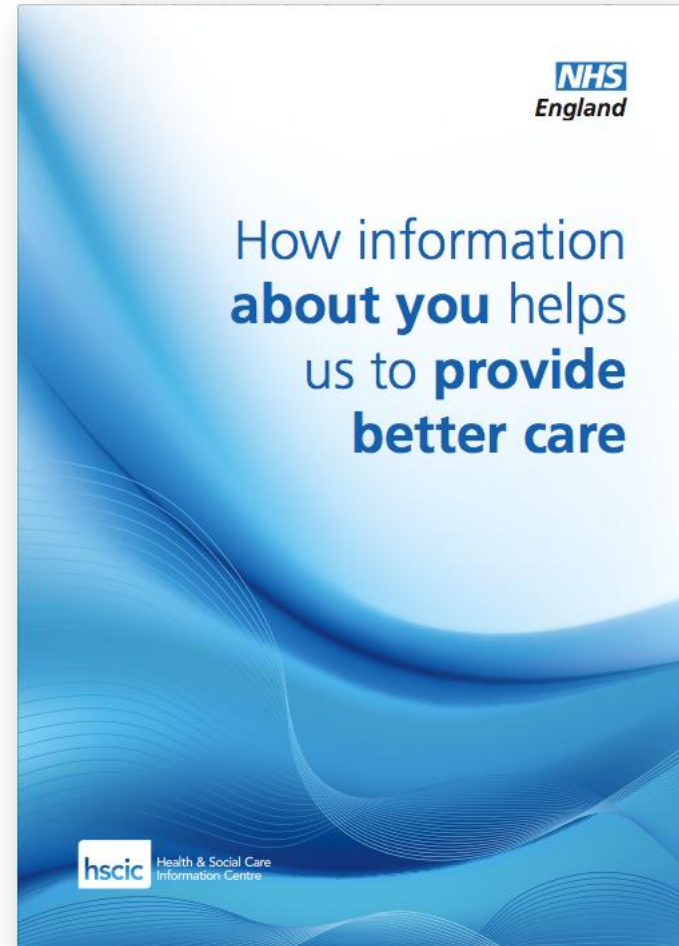
# Fair Processing

- 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
  - Household leaflet drop

The screenshot shows the NHS Choices website interface. At the top, there is a navigation bar with links for Home, About, Contact, Tools, Video, Choose and Book, and Communities. A search bar is present with the text 'Enter a search term' and a 'Search' button. Below the navigation bar, there are tabs for 'Health A-Z', 'Live Well', 'Care and support', 'Health news', and 'Services near you'. The main content area features a breadcrumb trail: 'You are here: The NHS in England / The NHS / The NHS Number / Health records / About health records / The care-data system'. The article title is 'Your records', with sub-tabs for 'Overview', 'Summary Care Records', 'What to do', and 'Sharing your information'. The article text discusses a modern information system for medical records, mentioning the Health and Social Care Information Centre (HSCIC) and NHS England. A sidebar on the right contains 'Useful Links' (NHS Choices links, Find GPs, etc.) and 'External links' (Guide to confidentiality, etc.).

## ■ Summary

- Transparency & participation is driven by world class data
- HES is an excellent resource from which to start
- We will develop a 'Care Episodes Statistics' data service by acquiring and linking data across health and social care settings
- We will continue to include high standards of Information Governance in handling patient level
- GP data will start to flow soon
- Patients have rights to object
- Awareness raising continues

# ■ Questions



For more information, see:  
[www.england.nhs.uk/caredata](http://www.england.nhs.uk/caredata)

[peter.flynn@nhs.net](mailto:peter.flynn@nhs.net)



