**BCS Health – Open Debate**

Hospital Data and Datasets Collection

9 September 2013

# Agenda

- **Chair's introduction**
  - **Dr Justin Whatling**, Chair, BCS Health
- **Speakers:**
  - **Dr Geraint Lewis**, Chief Data Officer, NHS England
  - **Dr Phil Koczan**, CCIO, UCL Partners
  - **Pete Sinden**, CIO, Dr Foster
- **Breakout groups and open debate**
  - Practicality
  - Usage
- **Chair Conclusion**
- **Food and drinks networking**

# High quality care for all: now and for future generations

Geraint Lewis MD MPH
Chief Data Officer

September 2013

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

All parts of the English health and care system support the modernisation of care through the better use of data and technology
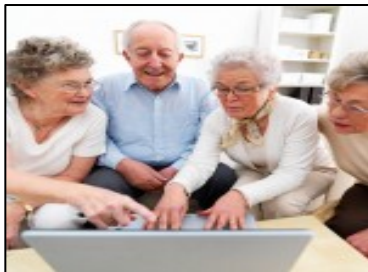
*The role of the ISCG is to commission services within an agreed strategic framework; and then to monitor delivery against set objectives*
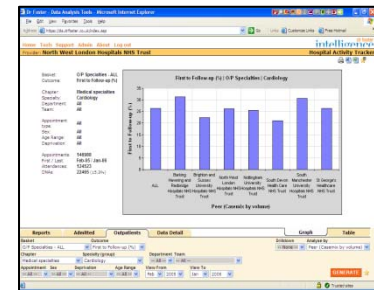
# Securing a world class health service



World class data
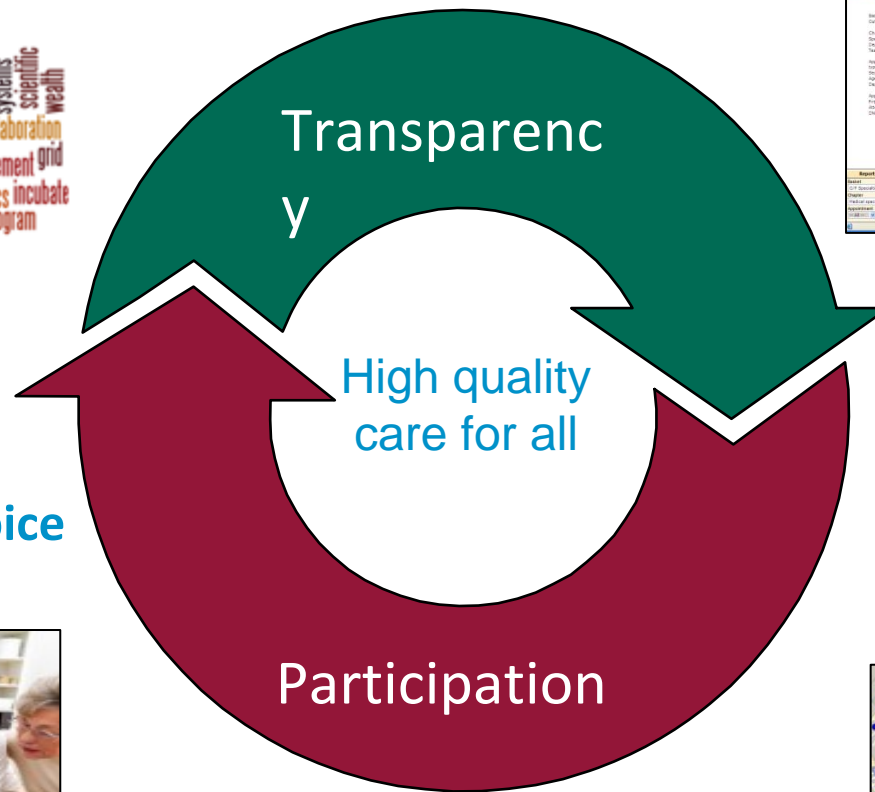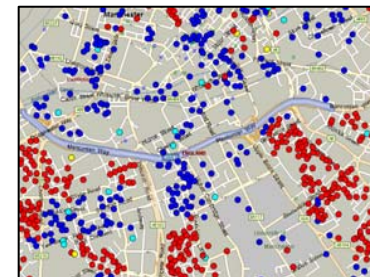
Open Outcomes

Customer choice and control

Patient Voice and Insight

Transparency

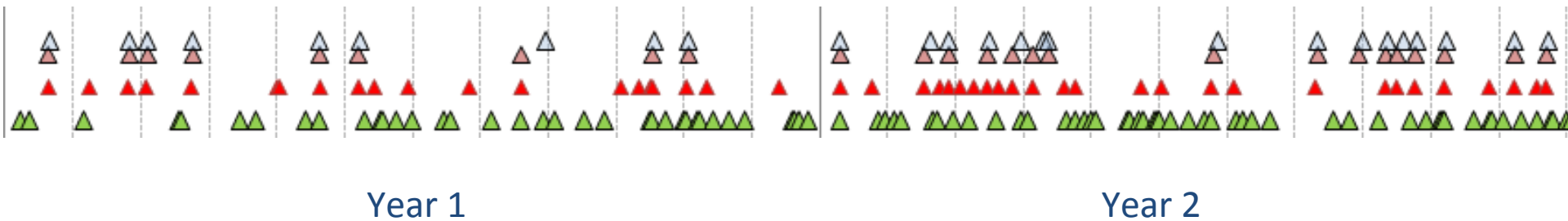Participation

High quality care for all

# Our starting point for world class data: Hospital Episode Statistics

- Hospital Episode Statistics (HES) is a world-class data warehouse containing details of all hospital activity in England

- Primary purpose is healthcare analysis for the NHS and government

- Records every **inpatient** 'episode' (1989 onwards), **outpatient** attendance (2003 onwards) and **ER** attendance (2007 onwards)

- Invaluable research tool – tens of thousands of peer-reviewed articles and audits
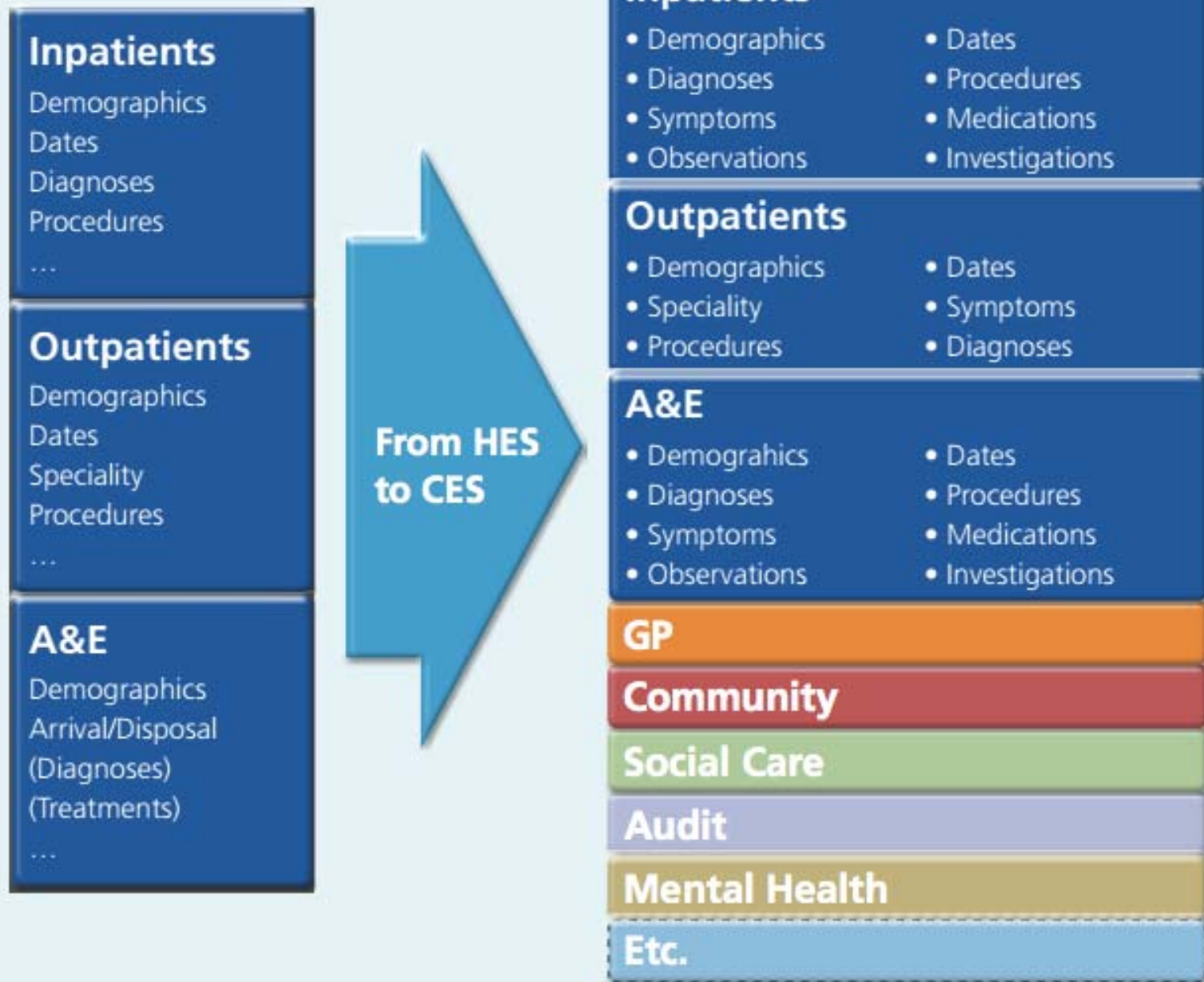


Dame Edith Körner (1921-2000)

# Underlying data – one individual



Year 1                                         Year 2

△ Inpatient - discharge

△ Inpatient - admission

▲ A&E visit

△ Outpatient visit

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

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

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

**From HES to CES**

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

**Outpatients**
- Demographics
- Speciality
- Procedures
- Dates
- Symptoms
- Diagnoses

**A&E**
- Demograhics
- Diagnoses
- Symptoms
- Observations
- Dates
- Procedures
- Medications
- Investigations

**GP**

**Community**

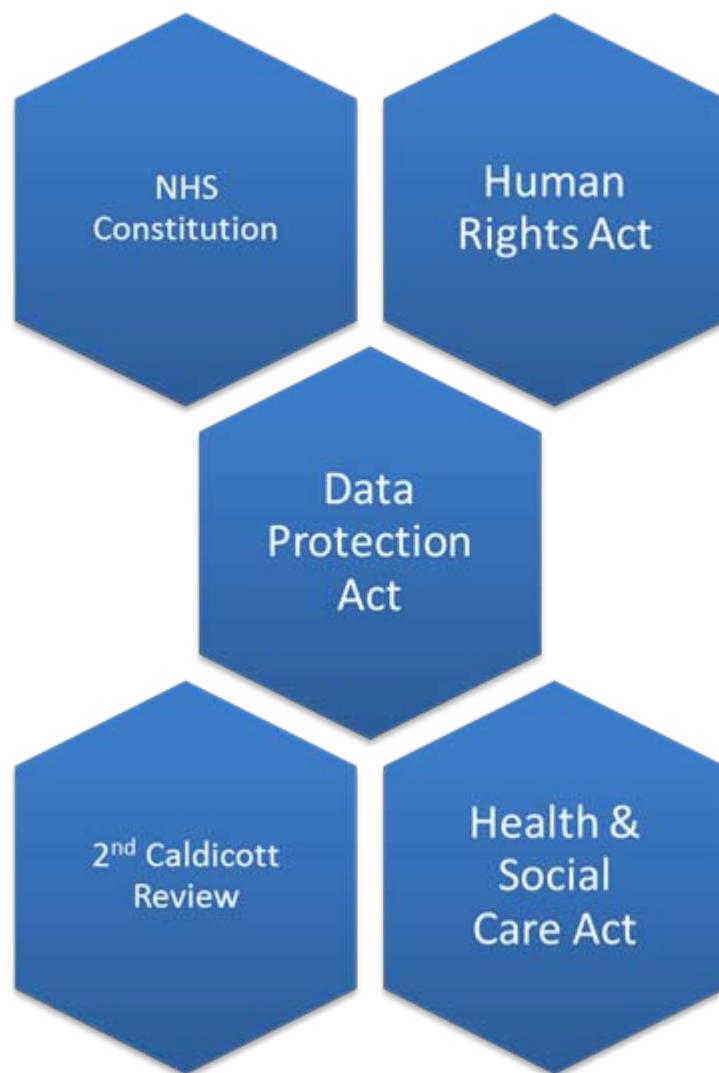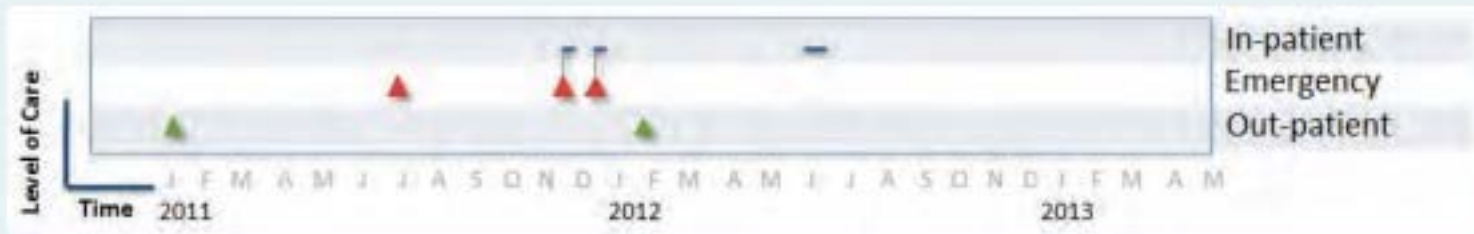**Social Care**

**Audit**

**Mental Health**

**Etc.**

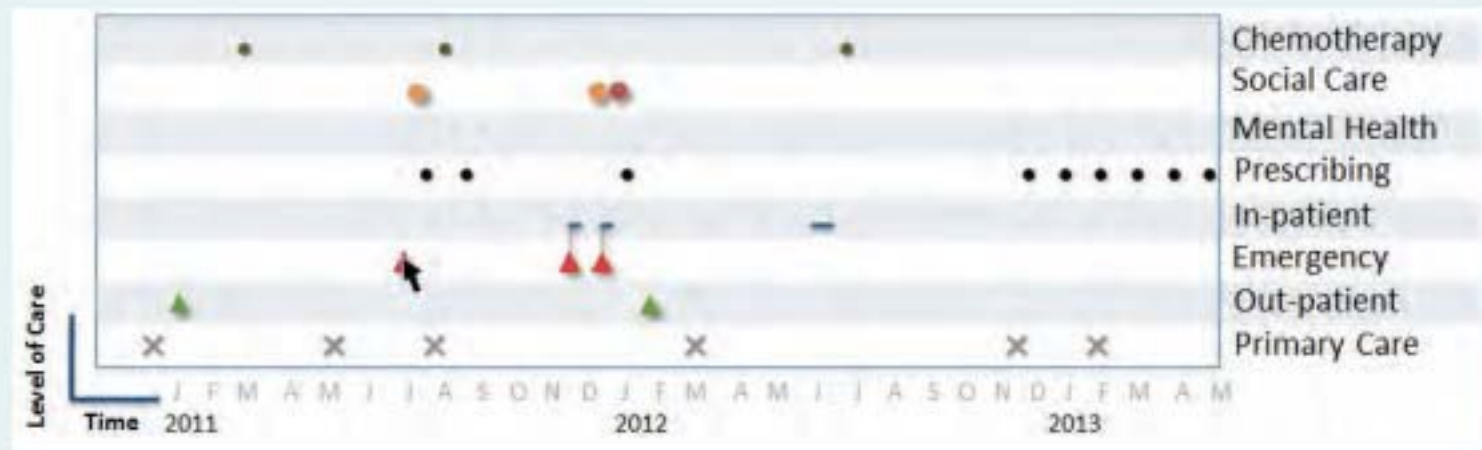**Figure 2:** Transformation of HES into CES as part of the care.data programme

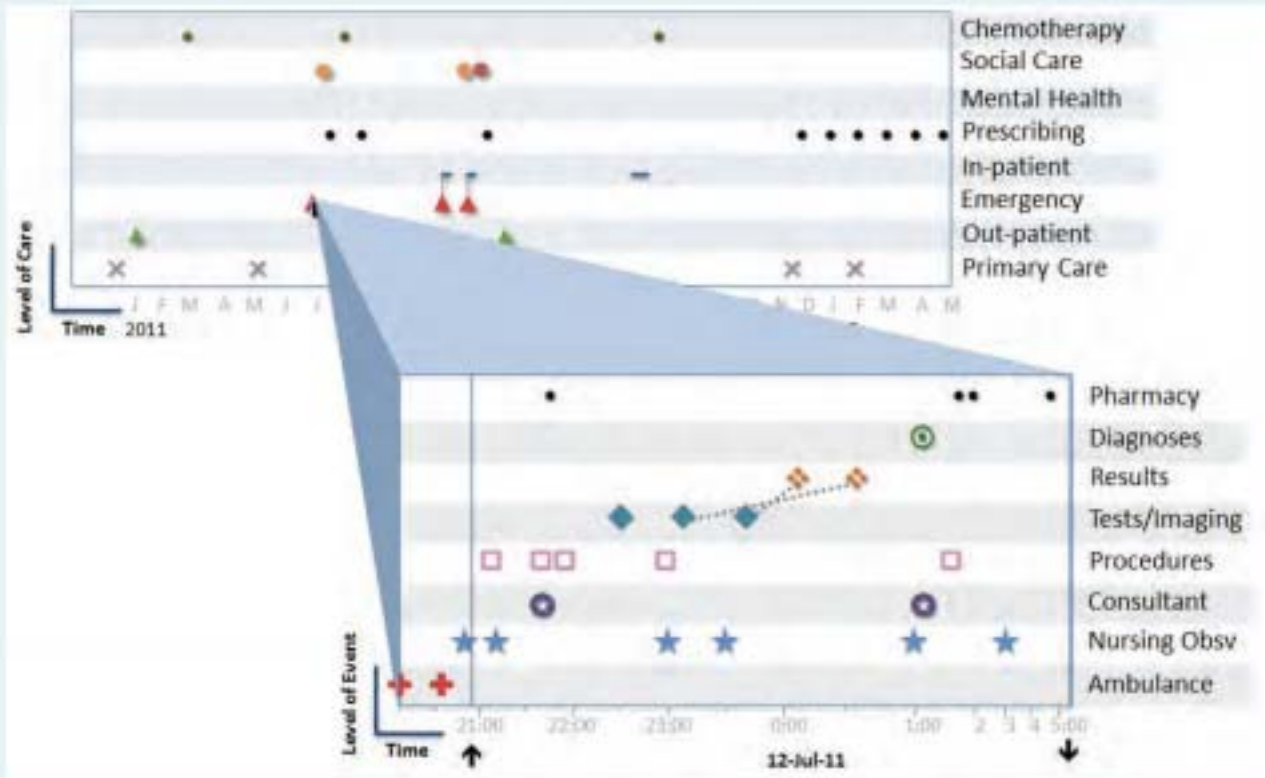The care.data programme is designed to comply with the highest standards of information governance :

**Figure 3:** Mock-up HES Theograph for one individual's hospital encounters, spanning two years
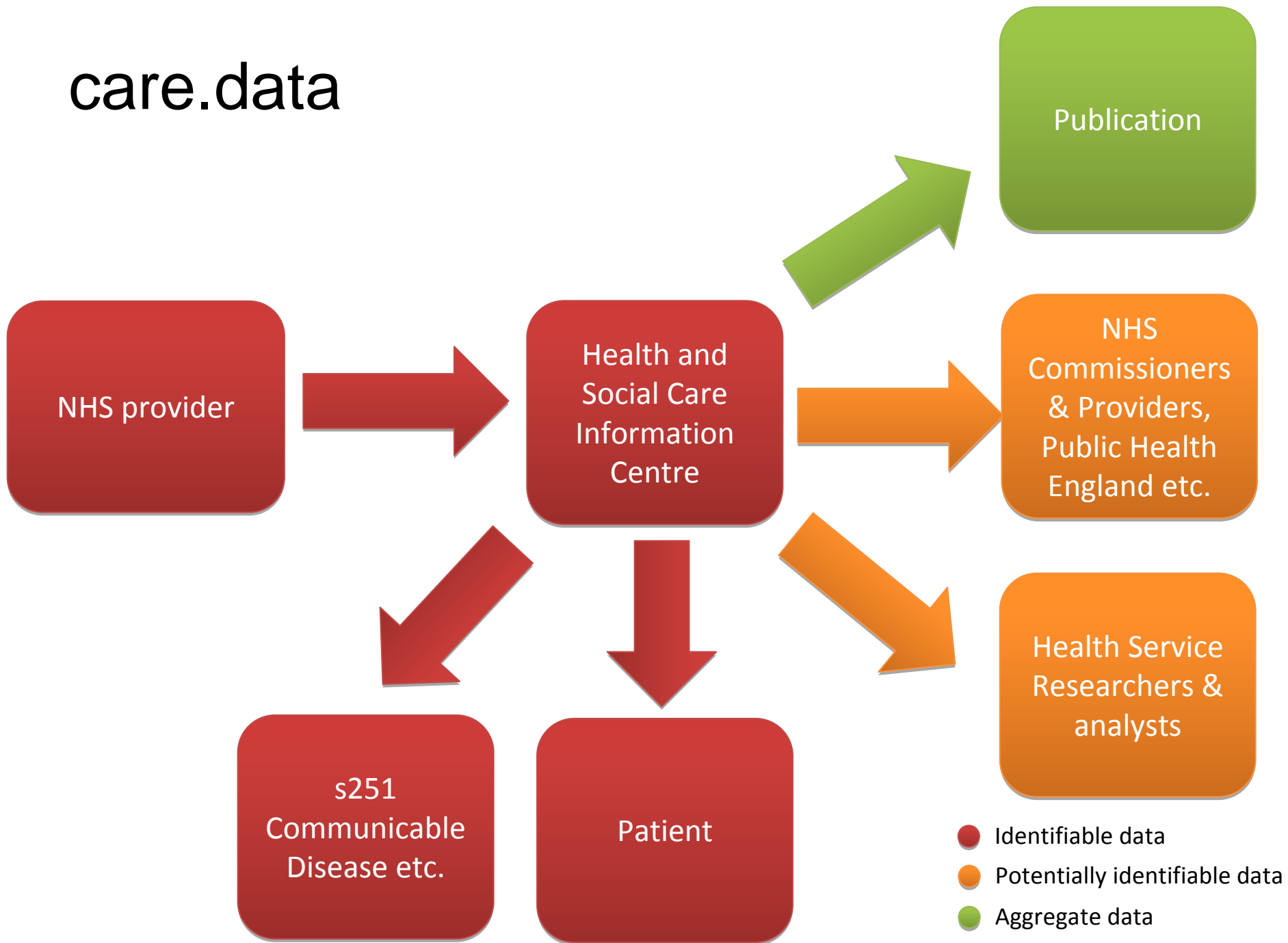
**Figure 4:** Mock-up CES Theograph for one individual's hospital, primary care, and social care encounters, spanning two years

**Figure 5:** Mock-up CES Theograph, showing minute-by minute details of the care received during an A&E attendance

# care.data

NHS provider → Health and Social Care Information Centre

Health and Social Care Information Centre →
- Publication
- NHS Commissioners & Providers, Public Health England etc.
- Health Service Researchers & analysts
- s251 Communicable Disease etc.
- Patient

Legend:
- 🔴 Identifiable data
- 🟠 Potentially identifiable data
- 🟢 Aggregate data

# Current Hospital Data Collections

| Inpatient | Outpatient | A&E |
|---|---|---|
| NHS Number | NHS Number | NHS Number |
| Start Date (Spell) | Appointment Date | Arrival Date |
| | | Arrival Time |
| Age at CDS Activity Date | Age at CDS Activity Date | Age at CDS Activity Date |
| Code of Provider | Code of Provider | Code of Provider |
| Code of Commissioner | Code of Commissioner | Code of Commissioner |
| Primary Diagnosis | Primary Diagnosis | Primary Diagnosis |
| Primary Procedure | Primary Procedure | Primary Procedure |
| Episode Start Date | | A&E Investigation – First |
| Episode End Date | | A&E Treatment - First |
| Age on Admission | | |

# Potential Future Collections

| Type of information | Details |
| --- | --- |
| Identifier | • NHS Number is the sole identifier in use for all submissions |
| Clinical | • Extra clinical details such as presenting complaint, issues on discharge |
| Prescribing | • Prescribing information including medications and infusions prescribed during stay, take home medications etc. |
| Tests | • Tests and imaging performed in hospital<br>• Results of test and imaging |
| Ward | • Ward information such as where the patient stayed, the and the time of transfers between wards |
| Feedback | • Patient feedback (patient reported outcomes, patient experiences) |
| Incidents | • Incidents that occurred in hospital, such as falls and medication errors |
| Nursing | • Nursing observations performed (observations recorded in hospital)<br>• Nursing observation results (results of the observations recorded in hospital)<br>• Responsible nurse (the nurse responsible for the care of a patient)<br>• Associated AHPs (other health care professionals who cared for the patient in hospital) |
| Discharge | • Discharge details (arrangements made with GP, social care etc.)<br>• Issues on discharge (issues present at the time of discharge such as pressure ulcer) |
| Audits | • Clinical audit data and registers which span a wide range of care<br>• There are currently a wide range of these datasets which could be incorporated |

# Online Consultation Questions

» Section 1 – Respondent's details
» Section 2 – Existing data that are not currently extracted
» Section 3 – Data that are not recorded or submitted
» Section 4 – Issues with data submissions to HES
» Section 5 – Priorities
» Section 6 – Timeframes
» Section 7 – Consistency and completeness of data
» Section 8 – Additional Information

# Next Steps

- Online consultation available here:

  https://consultations.infostandards.org/nhs-england/hes/

- Stakeholder events

- Publication of publish a technical document and collection of standards

- Further information available from:

  england.cdo@nhs.net

# Hospital Data and Datasets Collection

Dr Phil Koczan – CCIO UCL Partners

9 September 2013

# BCS: Hospital Open Data Debate

Peter Sinden, CIO, Dr Foster Intelligence
9th September 2013

# This is fundamentally a good idea

In sequencing the DNA of the NHS, we can better understand and target improvements

# Concern: Focus on Cost

- ## Need to focus on the benefits

  - ➢ Understand the problems to be solved and work with clinicians to research the information required

  - ➢ As currently constructed the focus is on costs to defining, standardising, extracting, pooling, etc.

  - ➢ Focus on time to benefit

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# Concern: Constricted Vision

- Need to enable the vision for benefits

  - ➢ Either central control (?!)

  - ➢ Or stimulate the nation's talent to innovate

  - ➢ What is holding back innovation?

# Concern: Risk vs. Reward

- Lack of clarity raises risk for investment

- Need to understand:

  ➢ This dataset, made available on this date, under these conditions to this audience.

  ➢ And what will the centre NOT be doing?

  ➢ Current statements are highly ambiguous

# Concern: Accessibility

- 4 main areas of concern

  ➤ Unrealistic separation of research and commercial

  ➤ Conceptual IG issues

  ➤ HSCIC as the central hub for all data

  ➤ Practical poor service issues

  ➤ Hostage to success in linkage

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# Concern: Funding Sources

- Given the high degree of risk caused by lack of clarity, the private sector will not invest heavily in speculative developments

- Commissioners are still confused and while CSUs are aiming to become commercial entities, will not fund innovation for others

- Acute trusts are under financial pressure and the current focus here adds significant cost with limited short-term benefit

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# Recommendations

- Continue – fundamentally good idea, BUT

- Stimulate early value creation

- Involve a wide group of innovators

- Make the data easily accessible, responsibly

- Provide real clarity over the centre's role

- Recognise that commercial benefit = applied research

- Explicitly account for commercial entities in data flows

- Create an investment fund to balance the lack of free cash and high risk

# So which data should be collected?

- Suggestions in consultation are sensible

- Priority order for collection should be led by demand to create value adding services

- Demand must be stimulated by clarity and investment

- NHS England should be setting agenda and defining the problems to be solved: e.g. clinician engagement with data to improve outcomes

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**Open Debate**

## **Practicality**

- What data exists now and what are our priorities for data collection?

- What needs to be done to achieve the dataset - what are the challenges / barriers, resources and timelines?

- What data collections hold the most importance for accuracy, completeness and consistency of data and how can NHS England better support?

## Usage

- How can hospitals make use of this initiative to improve care and what are the benefits for engaging?

- How do hospitals need to change and how will this initiative enable hospitals to focus on the patient care pathway ?

- What does it achieve at a national level and what are the limits of its use?