



**NHS**

The  
Information  
Centre

for health and social care

**Clare Sanderson**  
Director of Information Governance  
**Developments in Information Governance**

# The NHS Information Centre - Who are we?

Established in 2005, The NHS Information Centre is the central authoritative source of health and social care information, acting as a 'hub' for high-quality, national and local, comparative data for all 'secondary uses'



The central, authoritative source of health and social care information.

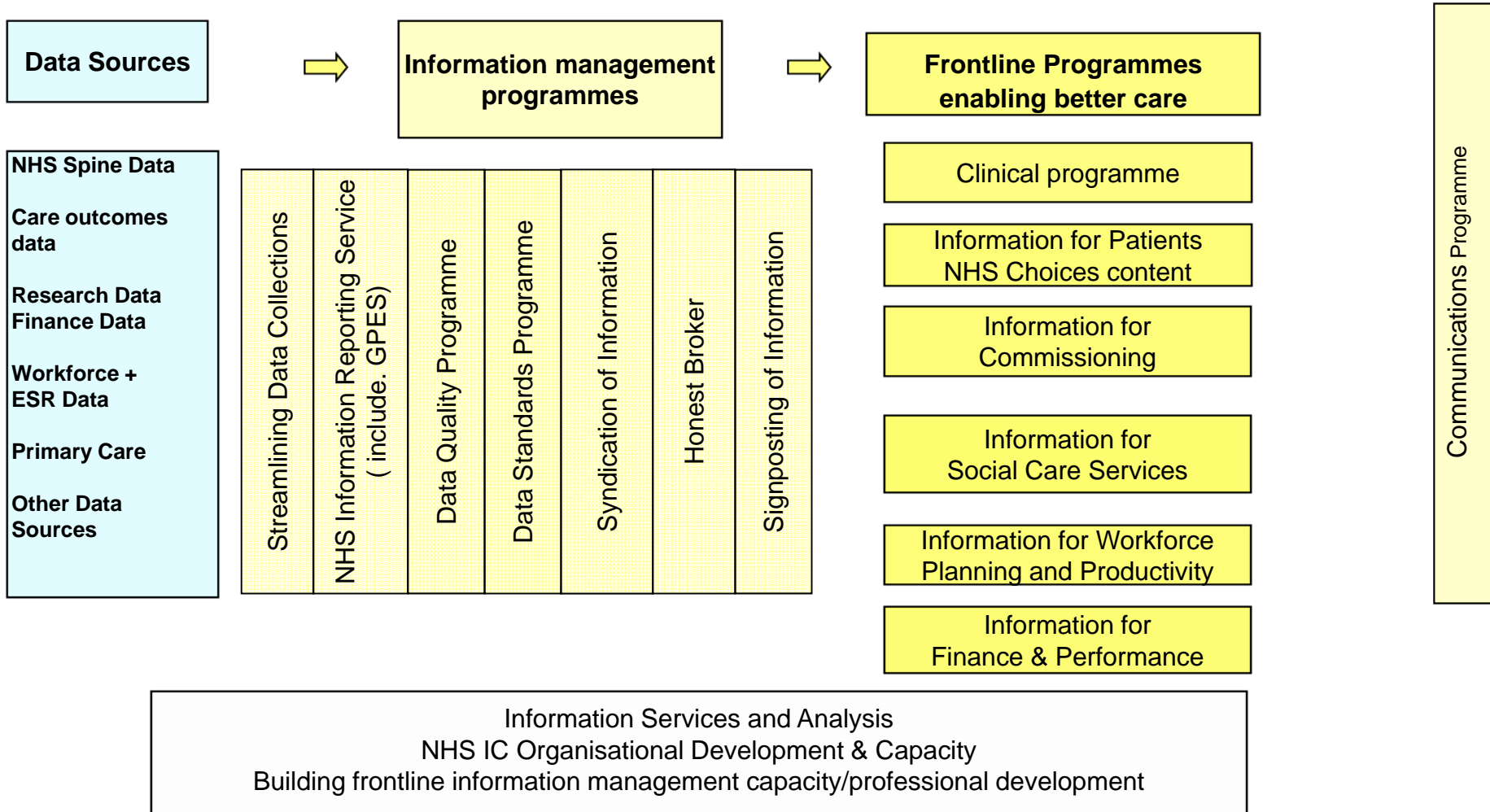
# Our products and services

The NHS Information Centre provide a wealth of products and services to help commissioners and providers improve patient and client care within the following areas:



The central, authoritative source of health and social care information.

# 2009/10 NHSIC Programmes



The central, authoritative source of health and social care information.

# Our role

## Quality & Standards

Ensuring the right information quality, governance and standards in data and data collections

## Access

Improving access to and interpretation of data through better presentation and reporting  
Ensuring fair and equal access to the information

## Delivering solutions

Work collaboratively alongside customers and partners to best utilise our information to tailor make solutions

## Data and Data Collection

The central, authoritative source of health and social care information.

# What is Information Governance?

*“the structures, policies and practice of the DH, the NHS and its suppliers to ensure the confidentiality and security of all records, and especially patient records, and to enable the ethical use of them for the benefit of individual patients and the public good”.*

# In the context of much publicised data losses..

Prime Minister Gordon Brown has said he "profoundly regrets" the loss of 25 million child benefit records

The loss of discs containing personal details of 25 million people was "entirely avoidable", a report says.

**The information commissioner has told the NHS to improve its data security, after breaches involving the loss of thousands of personal medical records**

The information lost by the HMRC could prove very valuable to fraudsters, computer security experts say

Over twenty years worth of personal information relating to workers at Queen Mary's Hospital in Sidcup has gone missing.

A hospital trust in Cambridgeshire has been ordered to tighten security after a memory stick with medical treatment details of 741 patients went missing.

# Our Policies .....

- Information Security
- Information Risk
- Legal Compliance
- Data Access and Information Sharing (including re-use)
- Document and Records Management
- Statistical Governance



# Legal Compliance.....

- Data Protection Act 1998

- Fair and lawful processing
- Processed for specific lawful purposes
- Adequate, relevant not excessive for purpose
- Accurate and up to date
- Primary contact in obtaining data must ensure that
  - Not kept for longer than necessary
- Subjects know what is held and why
  - Processed in line with individual's rights
- Data is relevant, and policies exist for quality, archiving retentions and destruction
  - Secure
- Not transferred to other countries without adequate protection
- Subjects have the right to know what is held about them (40 days)

# Legal Compliance.....

- Data Protection Act 1998
- Common Law Duty of Confidentiality

**Form of law applied by reference to previous cases**

**Duty of confidence implies data cannot be disclosed unless**

- **The patient has consented;**
- **There is a legal duty to do e.g. a court order**
- **Overriding public interest.**

**Patients can bring legal action against the organisation and the individual responsible for any breach.**

# Legal Compliance.....

- Data Protection Act 1998
- Common Law Duty of Confidentiality
- The Human Rights Act 1998

**Article 8 of the Convention - the right to respect for private and family life contains four rights - respect for:**

- private life;
- family life;
- one's home;
- correspondence.

# Legal Compliance.....

- Data Protection Act 1998
- Common Law Duty of Confidentiality
- The Human Rights Act 1998
- Freedom of Information Act 2000

**Individuals have the right to request information from any public body**  
**Public body has obligations in responding to requests**  
**Creates exemptions from the duty to disclose**  
**Establishes arrangements for enforcement and appeal.**

**Individuals have the right to know if information requested is held and to be given that information within 20 working days.**

# Legal Compliance.....

- Data Protection Act 1998
- Common Law Duty of Confidentiality
- The Human Rights Act 1998
- Freedom of Information Act 2000
- Environmental Information Regulations 2004

## Similar to FOI Act but

- EIR relates to Environmental information only
- Charges can be made for EIR requests if reasonable.
- Requests may be verbal

# Legal Compliance.....

- Data Protection Act 1998
- Common Law Duty of Confidentiality
- The Human Rights Act 1998
- Freedom of Information Act 2000
- Environmental Information Regulations 2004
- Copyright Designs and Patents Act 1988

**Exists to provide protection for the owners of Intellectual Property Rights (IPR) – which protects the right of the copyright author in their work and at the same time allow others to access that work.**

# Legal Compliance.....

- Data **Section 251 of the NHS Act 2006 [formerly covered in Section 60 of the Health and Social Care Act 2001] permits the common law duty of confidentiality to be set aside in limited circumstances**
- Com
- The I **It enables the Secretary of State to support and regulate the use of confidential patient information in the interest of patients or the wider public good.**
- Free
- Envir **Section 251 provides a basis in law for patient identifiable information to be disclosed for specific purposes.**
- Copy
- Natic **The Secretary of State is required to consult with the independent statutory National Information Governance Board before making any regulations under Section 251**

# Legal Compliance.....

- Data Protection Act 1998
- Common Law Duty of Confidentiality
- The Human Rights Act 1998
- Freedom of Information Act 2000
- Environmental Information Regulations 2004
- Copy      **Provides for the effective re-use of public sector information**
- Natic      **Regulations apply in general only to information that is already available to the applicant.**
- Re-U      **Key principle is to permit re-use on the basis of the purpose of its re-use, not the identity of the re-user**

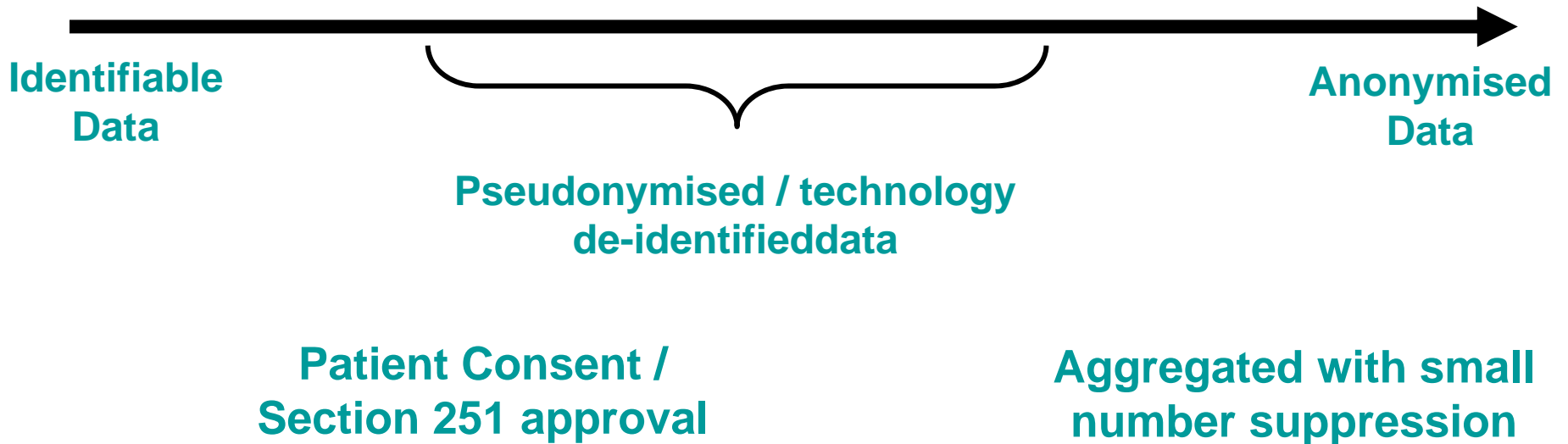


# Care Record Guarantee....

....makes commitments to patients about their records including:

- Access to records by NHS staff will be strictly limited to those having a need to know to provide effective treatment to patients
- In due course, patients will be able to block parts of their record to stop it being shared with anyone in the NHS, except in an emergency
- Individuals will even be able to stop their information being seen outside the organisation which created it – although doing so may have an impact on the quality of care they receive

# The 'Confidentiality Continuum'



# The National Information Governance Board and Section 251 Approval

- Statutory Body chaired by Harry Cayton
- Patient Information Advisory Board (PIAG) now the Ethics and Confidentiality Committee (ECC)
- Database Management Sub Group (DMSG) remains

# Patient Consent

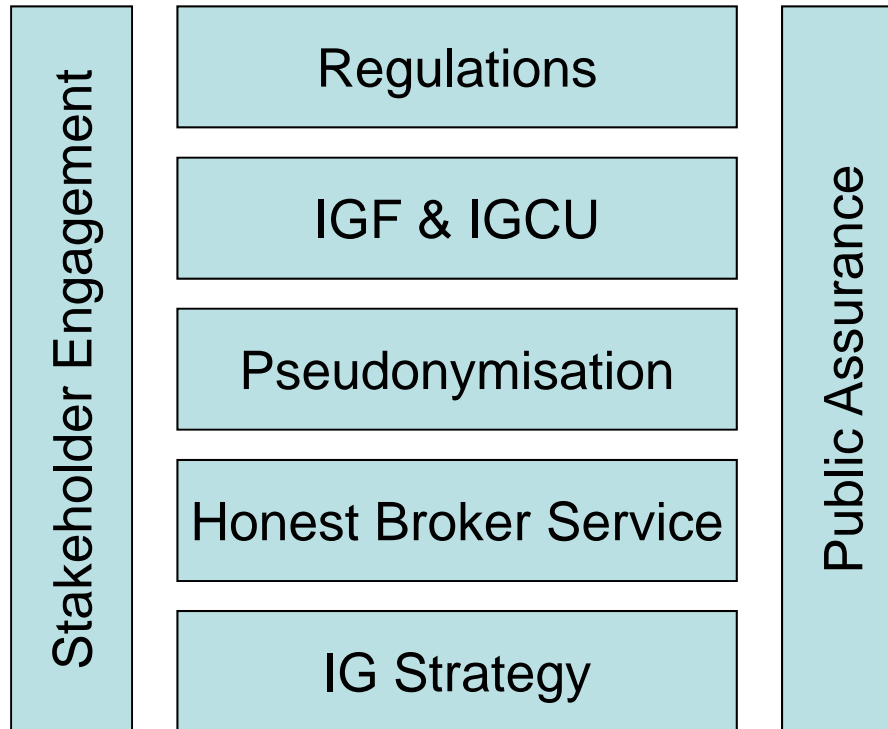
- Express Patient Consent
- Implied Patient Consent
- No Patient Consent !
- Section 251 approval

## Section 251 approval

Allows the Secretary of State for Health to make regulations to set aside the common law duty of confidentiality for medical purposes where it is not possible to use anonymised information and where seeking individual consent is not practicable.

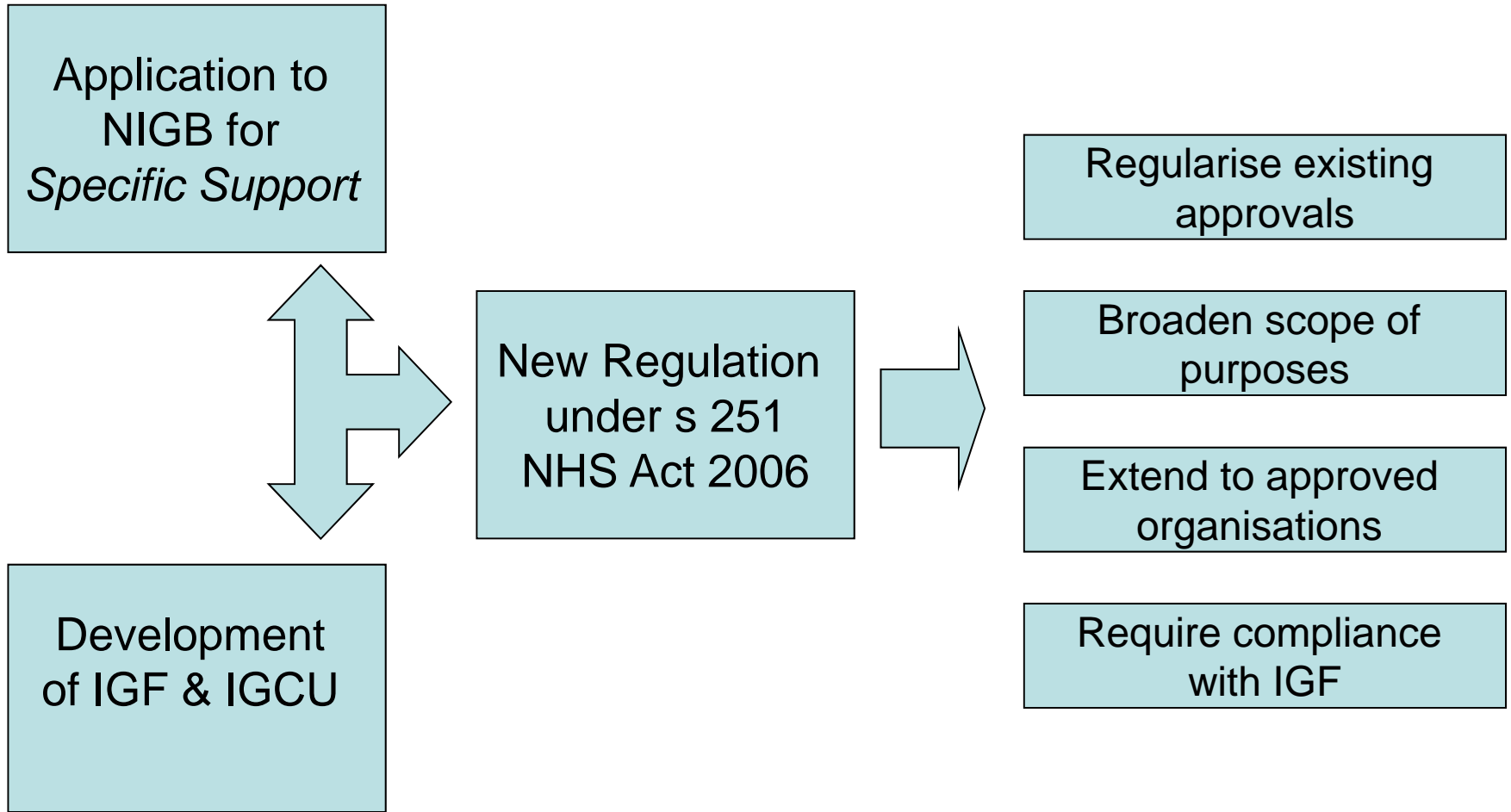
Under the Health and Social Care Act 2008, responsibility for administering these powers, was transferred from the Patient Information Advisory Group to the National Information Governance Board.

# Patient Confidential Information – the future?



The central, authoritative source of health and social care information.

# Regulations



# Regulations

- Duty of confidence in respect of processing confidential patient information may be set aside by NIGB ECC for defined purposes under s251.
- The process involves application to ECC in respect of purpose and data set.
- NHS IC is seeking specific support to lay Regulations in respect of current approvals, broaden the scope of purpose and extend processing to approved organisations including NHS IC and HRSS (RCP).
- NHS IC developing IGF and IGCU in collaboration with the RCP and expect Regulations to require compliance to IGF.



# Regulations

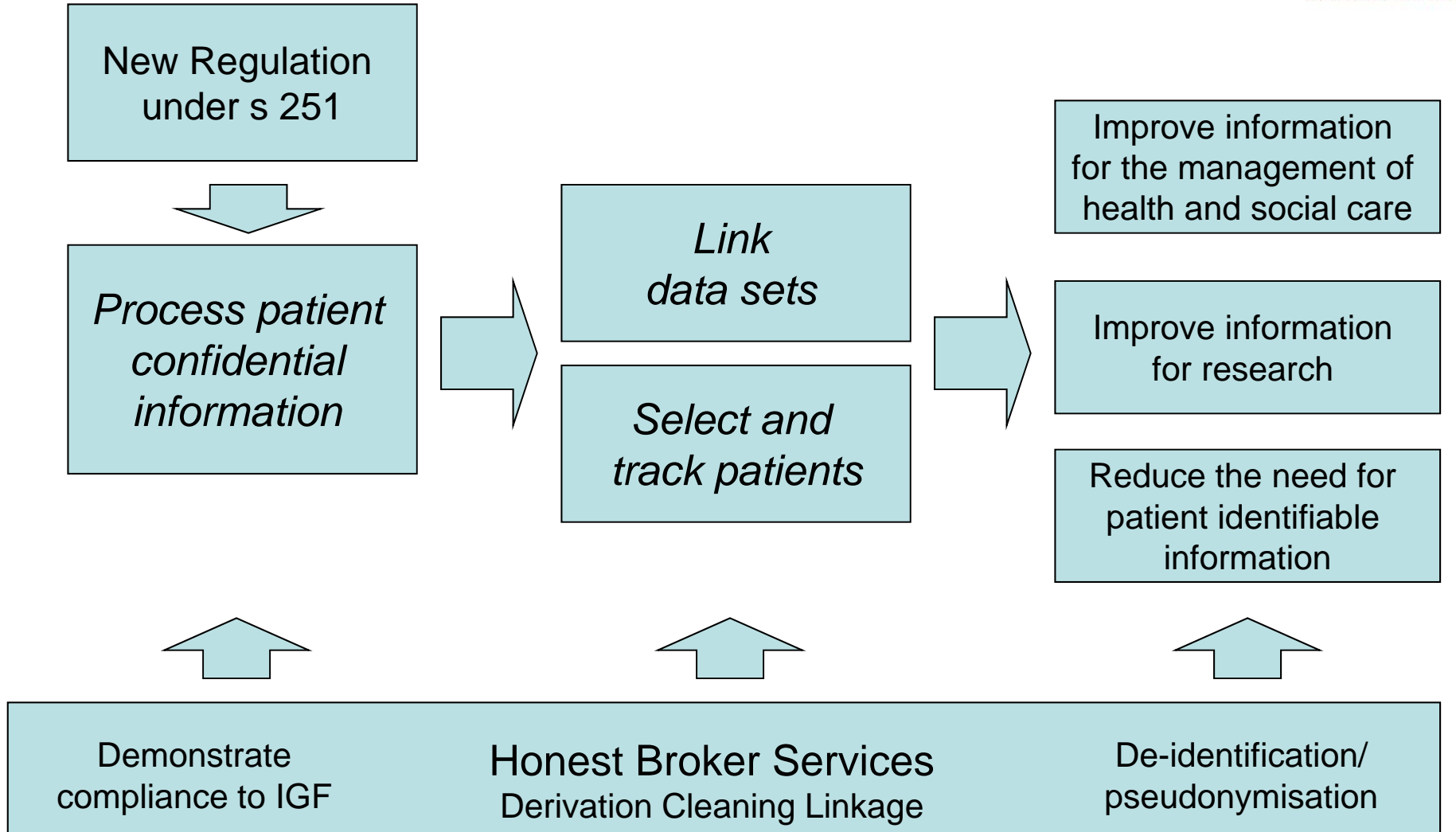
Under s 251 purposes must fall within the definition of medical purposes which includes:

- preventative medicine;
- medical diagnosis;
- medical research;
- the provision of care and treatment; and
- the management of health and social care.

The purpose must be

- in the interests of improving patient care; or
- in the public interest

# Post Regulations



The central, authoritative source of health and social care information.

# Honest Broker Programme

## Objectives

Process patient confidential information to robust information governance standards

Improve provision of information for medical research and the management of health and social care

## Benefits

IG Assurance

Enhanced Capability

Information for NHS

Information for Research

Contribute to Streamlining Information Processes

Contribute to Streamlining Service Processes

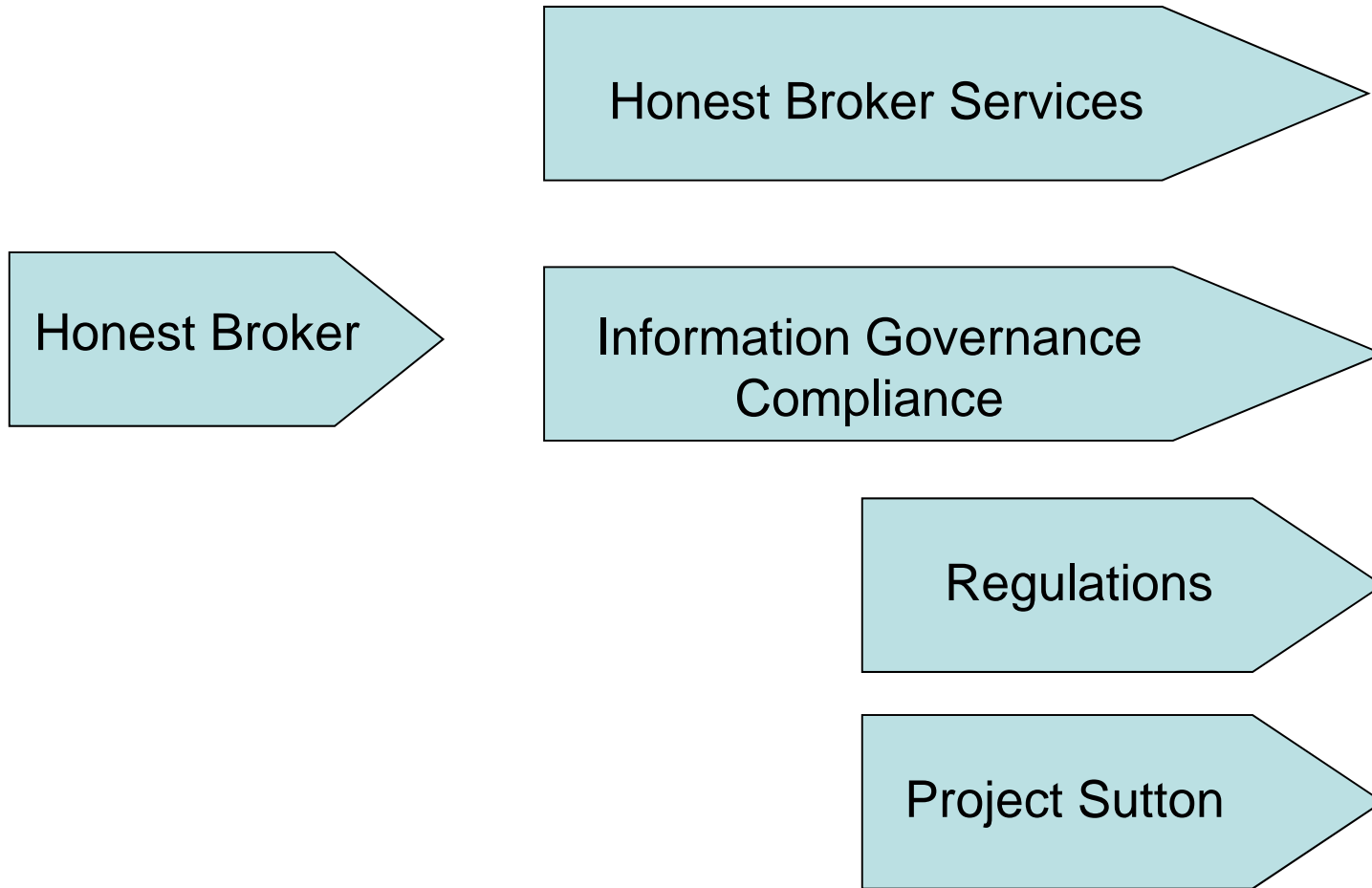
Public Confidence

Reputation

Strengthening the NHS IC

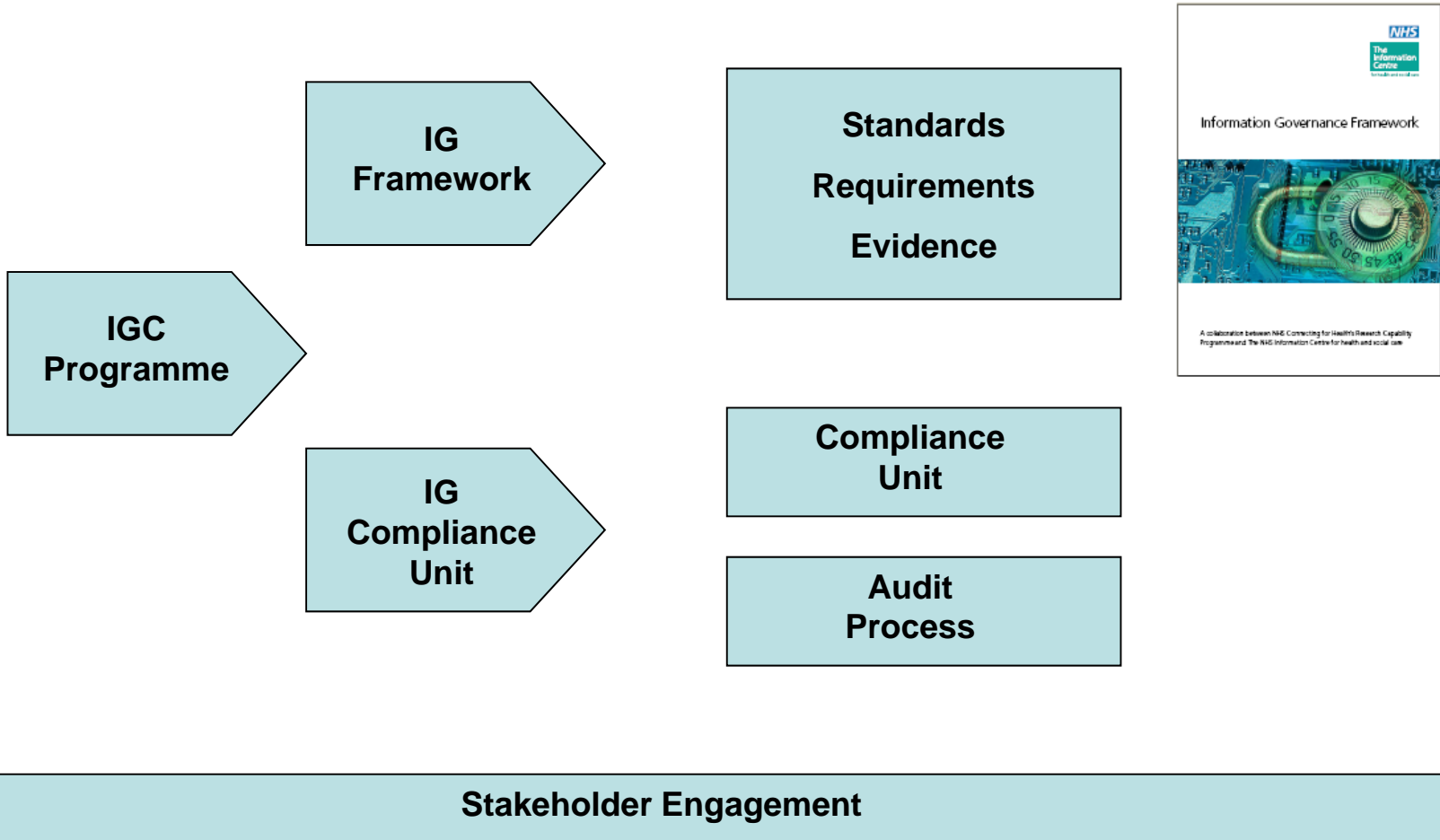
UK Health Research

# Honest Broker Programme Structure

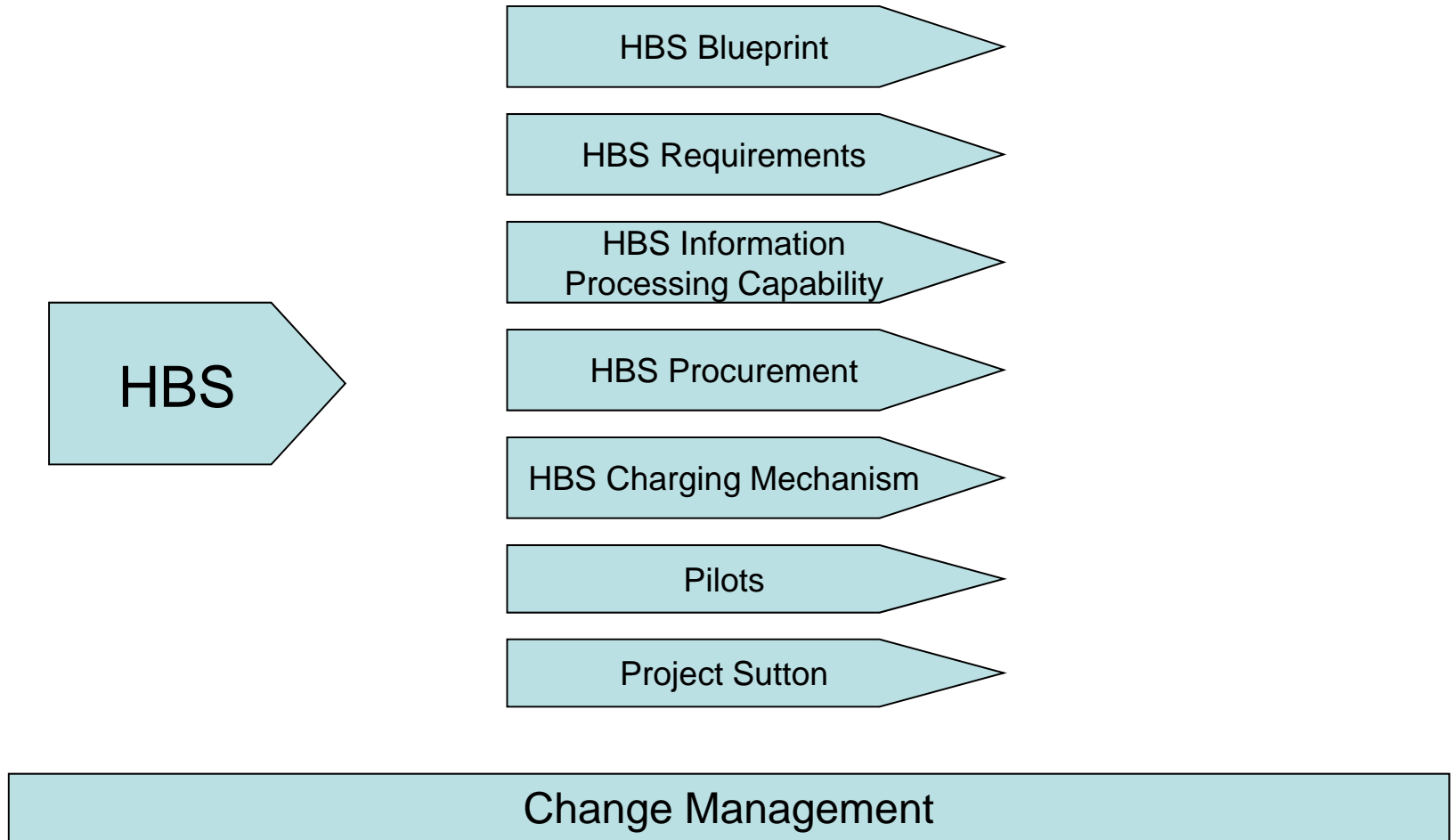


The central, authoritative source of health and social care information.

# Information Governance Compliance

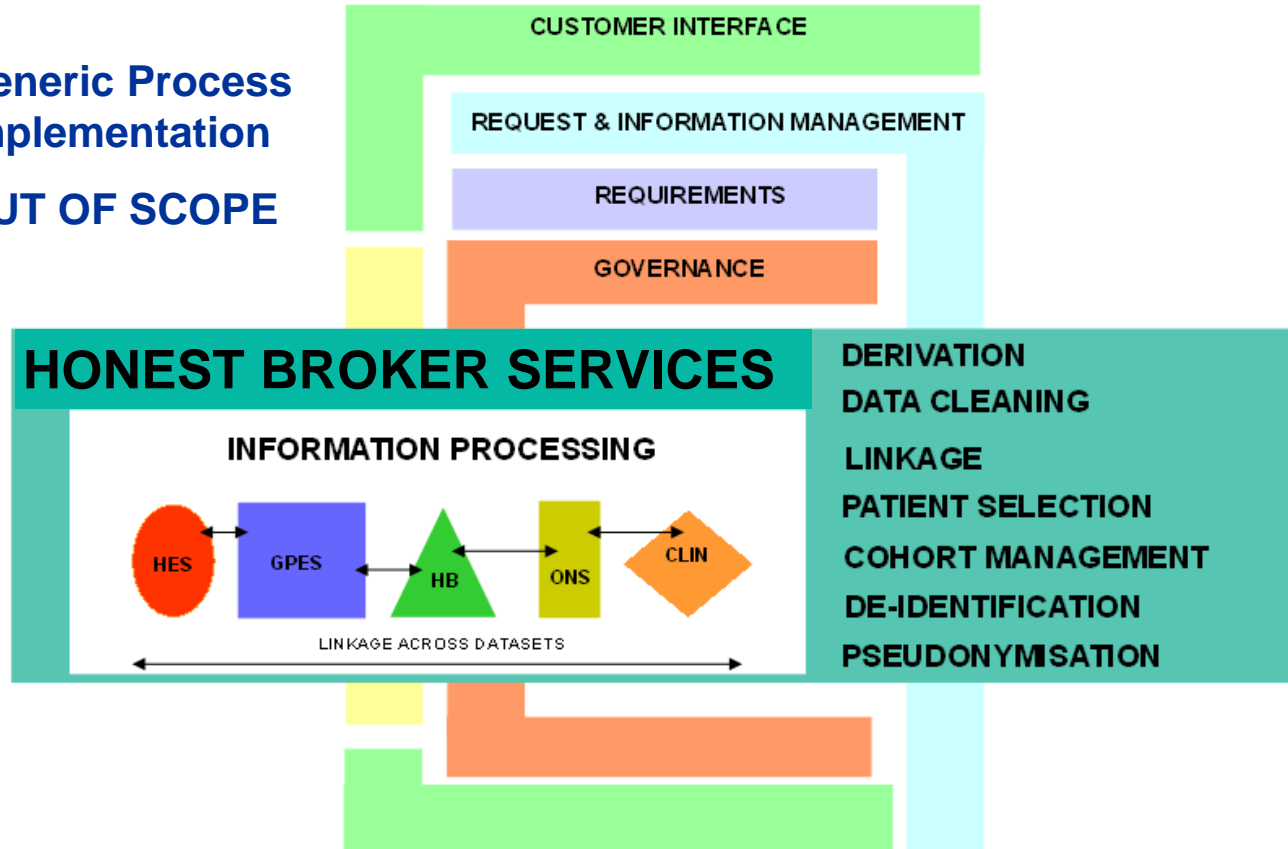


# Honest Broker Services



# HBS Blueprint

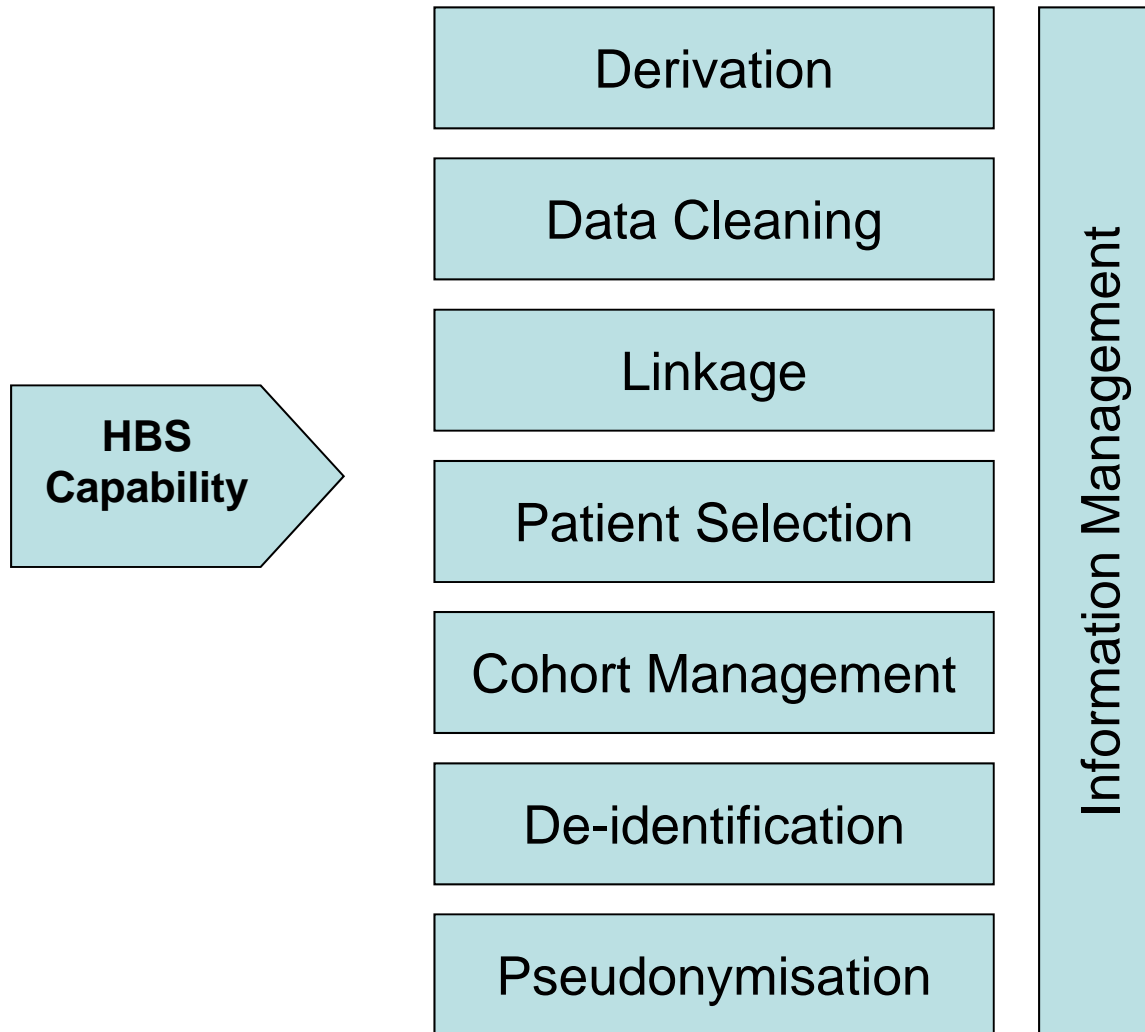
**Generic Process Implementation**  
**OUT OF SCOPE**



**HBS Information Processing**  
**IN SCOPE**

The central, authoritative source of health and social care information.

# HBS Capability



The central, authoritative source of health and social care information.



# Pseudonymisation Implementation Project

## OPTION 1

Pervasive single pseudonymisation service,  
centralised with distributed processing capability;  
all secondary use pseudonymised centrally prior to loading into local  
systems,  
Small set of NHS wide pseudonyms

## OPTION 2

Parallel national and devolved local pseudonymisation services;  
NHS standards in compliant local secure environments, meeting IG  
Framework standards;  
Pseudonyms locally generated prior to loading into local secondary use  
systems and different between local health communities

# Pseudonymisation Implementation Project

## Benefits of recommended option:

A solution that is applicable to all flows of identifiable data for secondary use purposes across the NHS

Support for patient safety through more effective local DQ, linkage and derivation

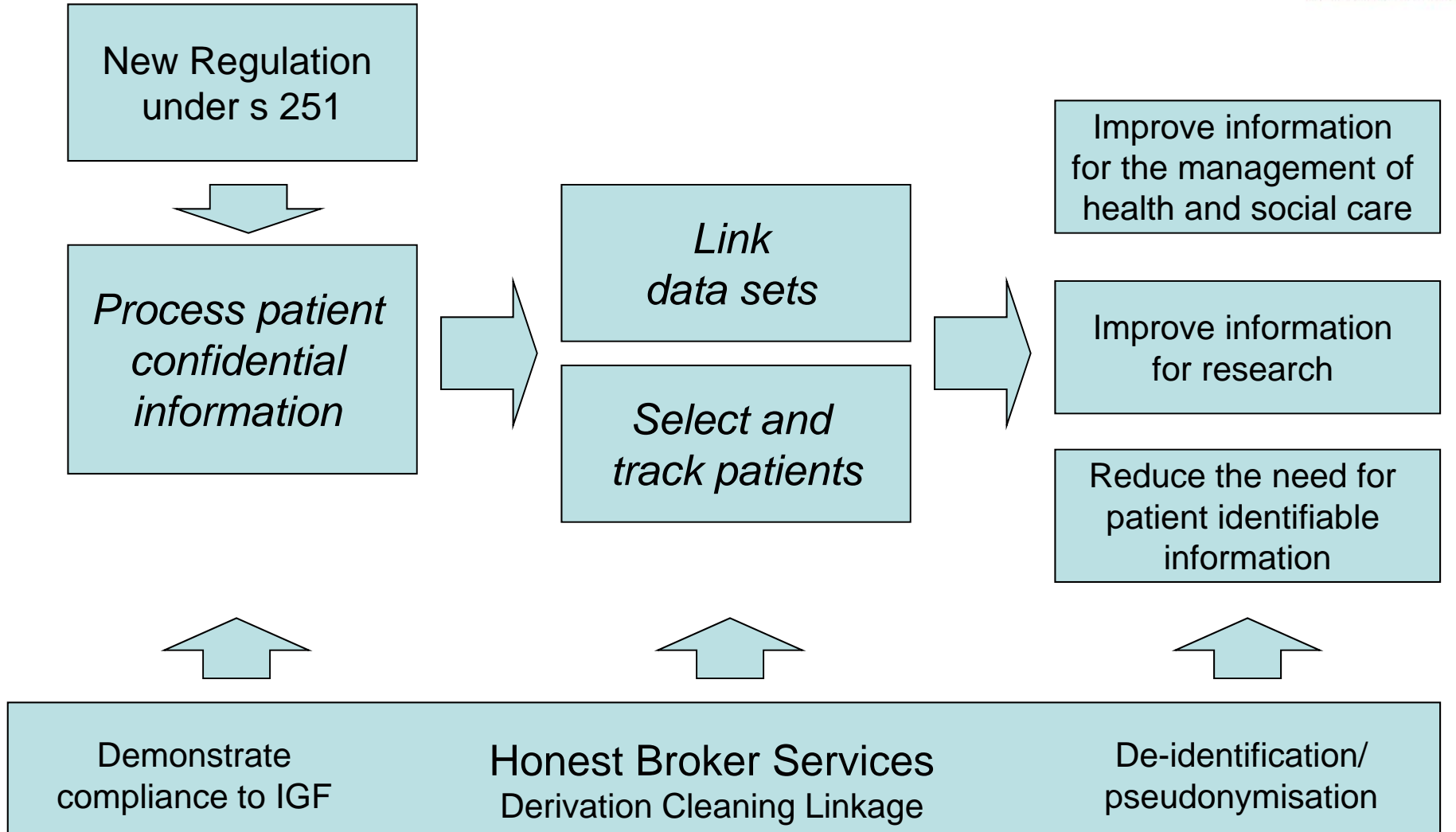
Marginal increased risk of pseudonym breach but with significantly lower impact and improved recovery

Reduced impact on NHS business processes  
flexible support for policy developments and local implementation

Increased technical feasibility

Improved implementation opportunities

# A vision of the future?



The central, authoritative source of health and social care information.



The  
Information  
Centre

for health and social care

**Find out more**  
**0845 300 6016**  
**[www.ic.nhs.uk](http://www.ic.nhs.uk)**

The central, authoritative source of health and social care information.