Public Health England

Who can access your data and how?

Rachael Brannan, Office for Data Release, Public Health England

rachael.brannan@phe.gov.uk

@PHE_UK

Public Health England

- When to share?
- What to share?
- Who to share with?
- Avoid ‘surprises’..

Public Health England

PHE Office for Data Release

Responsible for ensuring requests for personal information are processed legally, securely, efficiently and effectively.

- Under the Data Protection Act (1998) all personal and confidential information relating to living individuals must be held, used and accessed fairly and securely and treated with respect. (Statute Law)
- A duty of confidentiality extends beyond the death of a patient (Common Law)
- Caldicott Principles – ‘to share or not to share’

Public Health England

Conceptually, data protection is simple

- Data Protection is about protecting people by responsibly managing their data in ways they expect and understand
- In order to achieve this, the law prescribes certain standards and rules.
- As a data controller, PHE through the Office for Data Release applies these rules to each application we receive for data.

Public Health England

Data Protection Principles

1. Processed fairly and lawfully
2. Processed for specified purposes
3. Adequate, relevant and not excessive
4. Accurate and kept up to date
5. Not kept for longer than necessary
6. Processed in accordance with the rights of data subjects
7. Protected by appropriate security (practical and organisational)
8. Not transferred outside the EEA without adequate protection

Public Health England

Caldicott Principles

- Justify the purpose of using confidential information
- Only use it when absolutely necessary
- Use the minimum information required
- Allow access on a strict need-to-know basis
- Always understand your responsibility
- Understand and comply with the law
- **The duty to share information can be as important as the duty to protect patient confidentiality**

Public Health England

The reality?

Public Health England

Can anyone guess how many data sets PHE has?

Public Health England

PHE processes over 100 unique datasets….

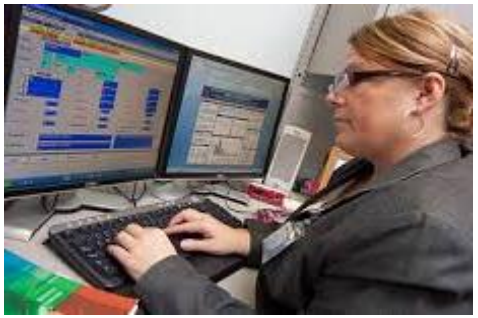
Communicable disease surveillance data

Lifestyle and behaviours

Notifiable diseases / organisms

Non-cancer screening

Cancer screening



Disease registration

Public Health England

Data available via ODR

- Cancer registration data, linked to:
  - Hospital Episode Statistics
  - ONS mortality data
- National Cancer Screening Programmes (Breast, Bowel and Cervical)
- National Drug Treatment Monitoring Dataset
- National Congenital Anomalies Register

Public Health England

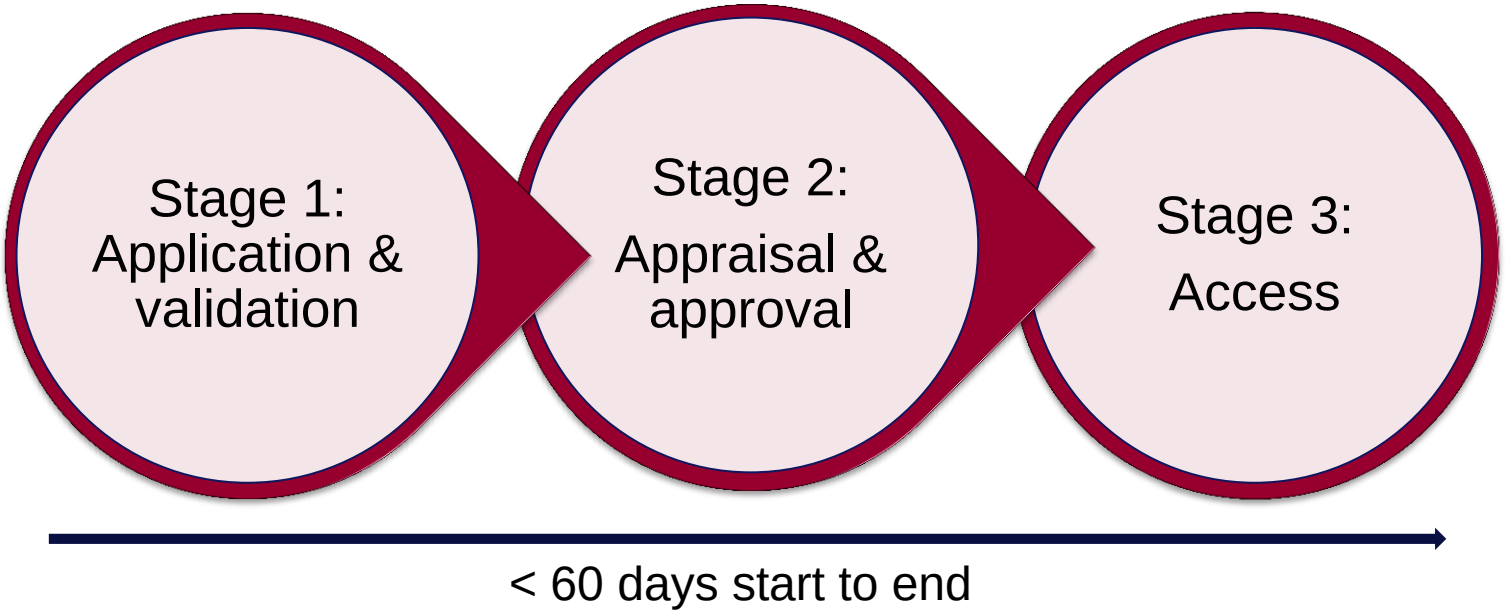
Research	Clinical Audit	Evaluation
• No universally agreed definition. • Creates new knowledge, which is generalisable • Requires Research Ethics Approval (REC)	• To assess the level of service against a set of predetermined standards. • Used/distributed locally in order to effect change to improve/change the level of service currently being provided. • Does not require ethical approval.	• Undertaken to benefit those who use a particular service • Designed and conducted solely to define or judge current service. • Does not require ethical approval.

Surveillance of communicable disease and other public health

Direct care

Public Health England

The Office for Data Release coordinates a three staged approvals process:



- The 3 stages are underpinned by pre-application advice
- ODR Standard Operating Procedure

Public Health England

Stage 1 – Application & validation

Public Health England

Protecting and improving the nation's health

ODR Data Request Form

Address:	PHE Office of Data Release FAO Rachael Brannan Public Health England Skipton House 2nd floor - Area D 80 London Road London SE1 6LH
Tel: 020 7654 8153	Email: ODR@phe.gov.uk

Overview

Title:			
First name:		Surname:	
Job Title:			
Email address:		Contact telephone number:	

Organisation name:		
Registered organisation address:		
Postcode:		
Organisation type:	☐ CQC Registered Health and/or Social Care Provider ☐ Local Authority ☐ Other Health and Social Care System Public Body ☐ Independent Sector Organisation	☐ Government Agency outside of Health and Adult Social Care ☐ Academic Institution ☐ Commercial ☐ Other
Sponsor/Funder: (name and address)		

Project title:	
Purpose for processing:	Please specify the objective for processing, methods, anticipated outputs and timescales for delivery (continue on page 4):
	☐ I have enclosed a copy of the project protocol ☐ I confirm that the data shall not be further processed in any manner incompatible with the purpose(s) outlined in the protocol
Data specification:	☐ I have enclosed a copy of the required data specification ☐ I confirm that the data specification is the minimum necessary to fulfil the purpose(s) for processing

End-use:	☐ Research ☐ Service Evaluation	☐ Clinical Audit ☐ Surveillance	☐ Other, please specify
Classification of data requested:	☐ Anonymised data	☐ Pseudonymised data	☐ Identifiable data
Data source:	☐ Cancer registration ☐ Cancer screening	☐ Congenital anomalies ☐ National Drug Treatment Monitoring Database	☐ Mortality data ☐ Other
Frequency:	☐ One - off ☐ Periodic - monthly	☐ Periodic - quarterly ☐ Periodic - annually	☐ Ad hoc - irregular dissemination ☐ Other

Public Health England

ODR form summaries:

- Applicant and organisation details
- Organisation type (i.e. Academic, charity sector)
- Funder

Processing activities

Data required and frequency

Proposed retention period

Data processor (named individual who will received the data)

Legal gateway (if applicable)

Research ethics committee approval

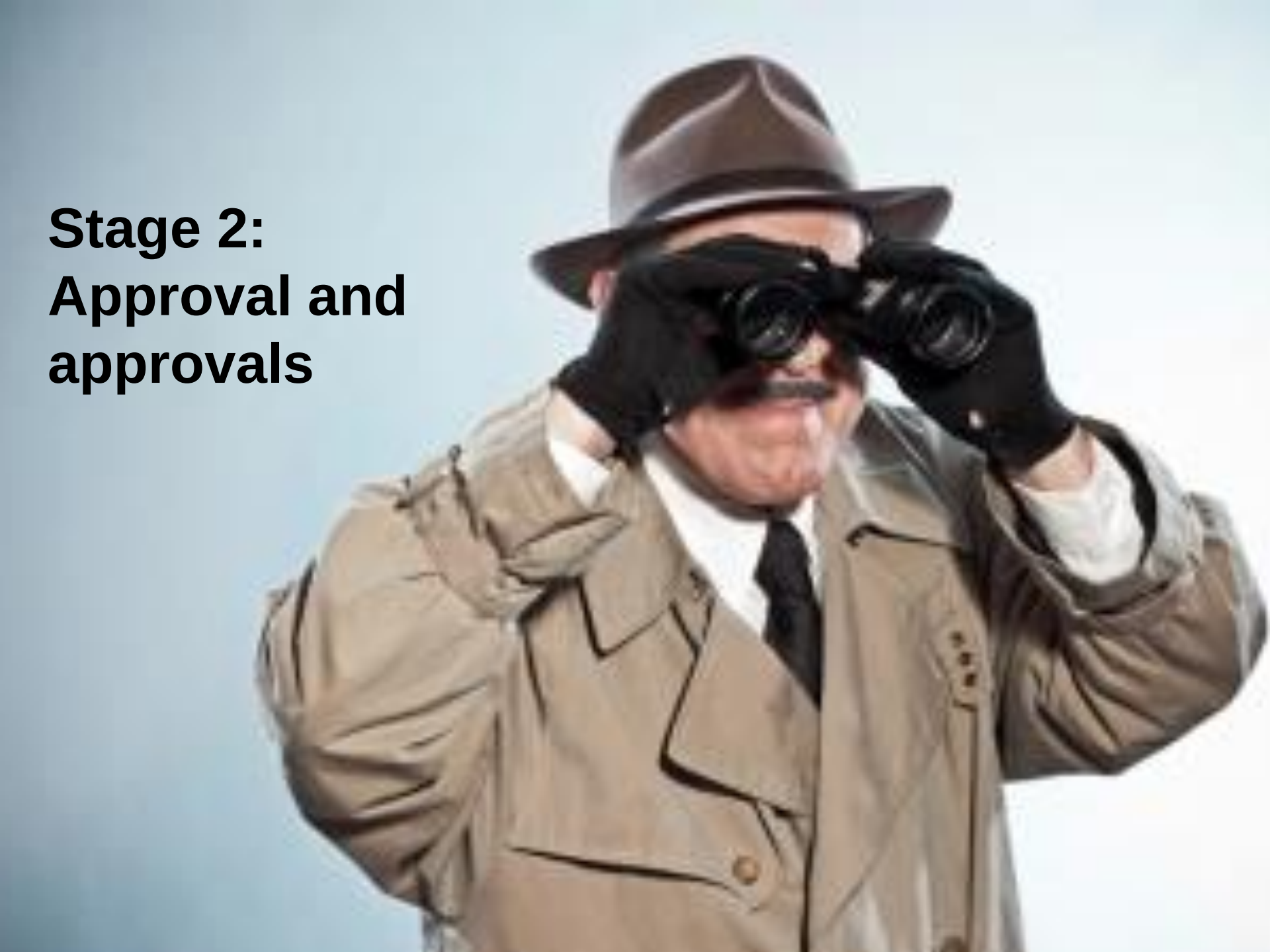
Security and data management

Public Health England

Alongside the ODR form…

- Detailed protocol
- Data specification – listing every field required
- Evidence of security and data management
- For identifiable data = a legal gateway
- For research = Research Ethics Committee (REC) approval

Stage 2: Approval and approvals



Public Health England

Principle 1: Processed fairly and lawfully

- Process data fairly and have legitimate grounds for collecting and using the data
- Must be transparent about the intention to use the data
- You must not do anything unlawful with the data

Public Health England

Principle 1: Processed fairly and lawfully

- The Act sets out ‘conditions for processing’, one of which must be complied with for processing to take place
- Set out in Schedules 2 and 3
- The safest route to compliance is to ensure the individual knows what will be done with their data at the point of collection
- **Informed consent = not a document, but a process**

Public Health England

When consent isn't practicable?

The Health Research Authority Confidentiality Advisory Group (CAG) will consider:

a) the age of records and the likely traceability of patients

(b) the number of records, and

(c) the possibility of introducing bias because of a low response rate or because particular groups of patients refuse, or do not respond to, requests to use their information.

anguage

Health Research Authority

Patients and the public | Research Community | REC and REC community | About us | Resources

us ▸ Our committees and services ▸ Section 251 and the Confidentiality Advisory Group (CAG) ▸ CAG Advice and HRA/SofS
val Decisions

ittees and services
1 and the
lity Advisory Group
e and HRA/SofS
ecisions
f previous ECC
f previous PIAG
ction 251?
bers

CAG Advice and HRA/SofS Approval Decisions

New guidance for CAG applicants and potential applicants on reducing the disclosure of confidential patient information is available here.

Details of all approvals are held in the Register of approved applications. It contains a summary of the activity, details of the identifiers approved and contact details for the applicant. If you are a data controller seeking confirmation on whether an application has been approved and the specific application details, you should obtain a copy of the approval letter directly from the applicant in the first instance. Applicants should also be asked to address queries about approval scope in the first instance. The Register details all applications that have received approval from the Secretary of State for Health or the Health Research Authority (HRA approvals from 1 April 2013). For convenience, the Register is divided into four documents as follows:

- April 2013 onward approved research applications (Excel, 996KB)
- April 2013 onward approved non-research applications (Excel, 798KB)
- January 2009 – March 2013 approved applications (advice provided by the NIGB ECC) (Excel, 3.43MB)
- 2001 – 2008 approved applications (advice provided by PIAG) (Excel, 2.39MB)

Please note that the register is updated once every two weeks. Please note that if you experience any difficulties accessing the above files we advise that you right-click on the link and click to save the file on your computer/network. You should then able to open the saved file. The minutes from each meeting will hold

Public Health England

Principle 2: Processed for specified purposes

"The personal data shall be obtained only for one or more specified lawful purposes and shall not be further processed in any manner incompatible with that purpose or those purposes"

- Identify the purpose in the protocol
- Ensure the purpose (i.e. research or direct care) in included in the notice to the Information Commissioner.

Public Health England

ico.
Information Commissioner's Office

The UK's independent authority set up to uphold information rights in the public interest, promoting openness by public bodies and data privacy for individuals.

Home | For the public | For organisations | Report a concern | Action we've taken | About the IC

About the ICO / What we do /

Register of data controllers

The Data Protection Act 1998 requires every organisation that processes personal information to register with the Information Commissioner's Office (ICO), unless they are exempt. Failure to do so is a criminal offence.

There are more than 400,000 registered data controllers. We publish the name and address of these data controllers, as well as a description of the kind of processing they do.

Search the register →

Public Health England

Principle 3: Adequate, relevant and not excessive

- Only request to process the information required for the purpose detailed
  - ‘Only ask for what you need!’ – must be justified
  - “just in case it might be useful one day!” – not acceptable
- By default – all data should be anonymised

Public Health England

	A	B	C	D	E	F	G
1	Cancer Registry Data						
2							
3							
4	**Variable Description**	**Variable Name**	**Details**	**Required (y**	**ICD codes this variable is required for**	**Time period this variable is requested for**	**Reason for request**
5	**PERSONAL DETAILS**						
6	GOLD patient Identifier	epatid	Unique patient identifier based on CPRD GOLD data	No - 14 Aug	C61 & D07.5	01 Jan 2001 - current	Linking
7	CR patient Identifier	cpatid	Unique patient identifier based on cancer registry data	No - 14 Aug	C61 & D07.5	01 Jan 2001 - current	Linking
8	Gender	sex		No - 14 Aug	C61 & D07.5	01 Jan 2001 - current	Linking
9	Age (at diagnosis)	ageatdiagnosis_years	Age in years at diagnosis, rounded down to full years	No - 14 Aug	C61 & D07.5	01 Jan 2001 - current	Linking and Exclusion
10	Age group at diagnosis	ageatdiagnosis_5_year_group	Age at diagnosis in 5 year groupings	No - 14 Aug	C61 & D07.5	01 Jan 2001 - current	Linking and Exclusion
11	Year of Birth	dob_year	Year portion of date of birth, where available	No - 14 Aug	C61 & D07.5	01 Jan 2001 - current	Linking and Exclusion
12	Ethnic Origin	reg_ethnicity	Follows 2001 census definition.	Y	C61 & D07.5	01 Jan 2001 - current	Descriptive Epidemiology
13	Embarkation year	embarkation_date_year	Year portion of NHS embarkation date, where applicable. The embarkation date is the date when the patient embarked from NHS treatment, e.g. emmigrated.	n			
14	Embarkation month	embarkation_date_month	Month portion of NHS embarkation date, where applicable. The embarkation date is the date when the patient embarked from NHS treatment, e.g. emmigrated.	n			
15	**DIAGNOSTIC, TUMOUR AND TREATMENT DETAILS**						
16	Diagnosis date	diag_date_format	Number of days from 'crd' in the CPRD GOLD dataset	Y	C61 & D07.5	01 Jan 2001 - current	Descriptive Epidemiology
17	Date of diagnosis flag	reg_diag_date_flag	Imputation of dates follows rules agreed by UKACR DQAR sub-group (August 2010). Blank field indicates that date imputation did not occur.	Y			To know what proportion of diagnoses dates were impu
18	Diagnosis month	diag_date_month	Month portion of diagnosis date, where available	No - 14 Aug	C61 & D07.5	01 Jan 2001 - current	Descriptive Epidemiology
19	Diagnosis year	diag_date_year	Year portion of diagnosis date, where available	No - 14 Aug	C61 & D07.5	01 Jan 2001 - current	Descriptive Epidemiology
20	Basis of Diagnosis	reg_basis_code		Y	C61 & D07.5	01 Jan 2001 - current	Descriptive Epidemiology
21	Screening status	reg_screening_status		n			
22	Screening category	screening_category	The value of the sub-classification of the screening flag. Populated where known when the value of the screening status is given as "Other". For breast screening service see: www.cancerscreening.nhs.uk/breastscreen/publications/nhsbsp62.pdf (page 4, section 2). For cervical screening service see: www.cancerscreening.nhs.uk/cervical/publications/nhsc	No - 14 Aug	C61 & D07.5	01 Jan 2001 - current	Descriptive Epidemiology

Sheet1 Sheet2 Sheet3

Public Health England

- Full date of birth (ddmmyyyy) **- Identifiable**
- Month and year of birth **- Potentially identifiable**
- 5 year age band at diagnosis **- Context? Other data held?**

For many secondary uses, it will be sufficient and practicable to disclose only anonymised or coded information.

Public Health England

Principle 4: Accurate and kept up to date

Public Health England

Principle 5: Not kept for longer than necessary

- Review procedures for retention and disposal
- Safeguard the confidentiality of personal data being destroyed

Public Health England

Principle 6: Processed in accordance with the rights of data subjects

- Rights of access to the data held
- Rights to object to processing likely to cause or causing harm
- A right to prevent direct marketing
- A right to object to decisions by automated means
- A right to have inaccurate data corrected or erased
- A right to compensation for damage caused by a breach of the Act

Public Health England

Principle 7: Protected by appropriate security (practical and organisational)

Sensitive data requires commensurate level of security

- Security: IT and non-technical
- Controlling access to information
- Staff selection and training
- Ensuring business continuity
- Detecting and dealing with breaches of security
- Confidentiality contracts with third parties

Public Health England

Principle 8: Not transferred outside the EEA without adequate protection

Beware of others without equivalent protection

Public Health England

ODR approval – what happens next?

Data Sharing Agreement (DSC)

- Information governance standards in the recipient organisation,
- Legal principles that apply
- Limits the secondary uses of the requested data
- Retention periods and destruction.

Public Health England

Should we share…

Scenario 1: A consultant oncologist requests cause of death information on his/her patients

Scenario 2: The University of Fibchester in the USA would like to send a patient reported outcomes survey to all breast cancer patients diagnosed in 2014.

Scenario 3: A UK health charity would like to publish less common cancer incidence by cancer site (split by age, sex and ethnicity and Lower Super Output Area (LSOA)).

Public Health England

Stage 3: Access to data for an approved data recipient

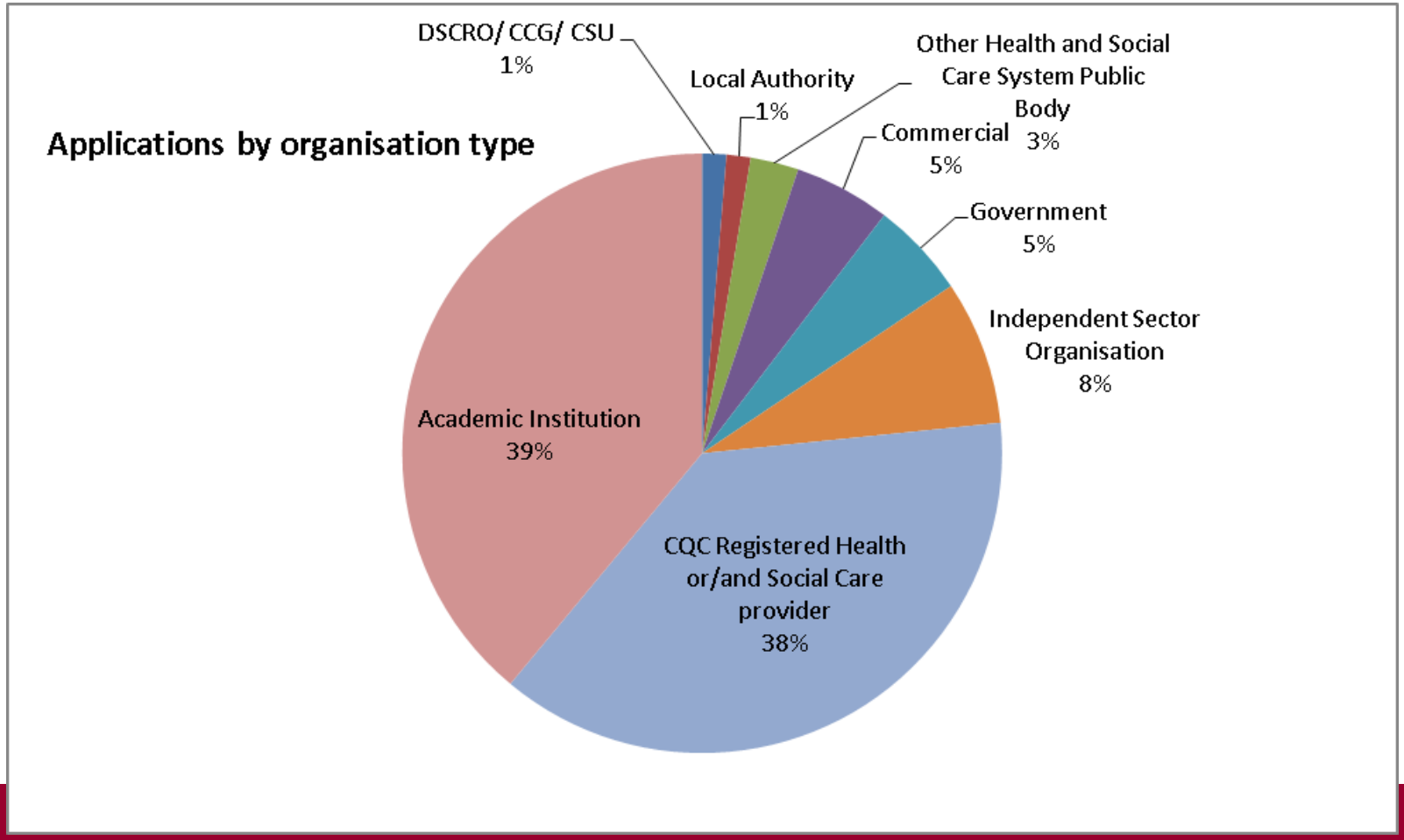
ODR approved over 70 requests in 2014/15

Data was released through secure mechanisms (i.e. encrypted, using the Secure File Transfer Service)

This represents around 30% of all requests that came to ODR

Public Health England

Who did we release to?



Public Health England

In 2015/16

Over 170 enquiries since April 1st 2015

- > 70 applications
- > 40 data releases